DOCUMENT RESUME

ED 311 158 CE 052 888

AUTHOR	Homans, Hilary; And Others
TITLE	Learning about AIDS. Interim Materials. Participatory Health Education Strategies for Health Educators with a Responsibility for Adult Education about AIDS and Update.
INSTITUTION	AIDS Virus Education & Research Trust, Horsham (England).; Health Education Authority, London (England).
REPORT NO	ISBN-0-903652-19-6
PUB DATE	87
NOTE	74p.
AVAILABLE FROM	AVERT, P.O. Box 91, Horsham, West Sussex RH13 7YR, England.
PUB TYPE	Guides - Classroom Use - Guides (For Teachers) (052)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Acquired Immune Deficiency Syndrome; *Disease Control; Foreign Countries; Health Activities; *Health Education; *Health Materials; Health Programs; *Health Promotion; Sex Education; Student Participation; Venereal Diseases
IDENTIFIERS	England

ABSTRACT

Intended for those who are responsible for educating other educators about AIDS (Acquired Immune Deficiency Syndrome), these materials are designed to result in learner-centered instruction about AIDS--helping students of all kinds explore their own anxieties about AIDS and consider the implications of factual information for their own behavior and lifestyles. The first chapter introduces the materials. The second chapter gives a rationale for a learner-centered approach to the teaching of AIDS and includes a brief overview of the AIDS epidemic and a description of several styles of health education. The third chapter provides statistics about AIDS; professional and medical explanations of AIDS; lay explanations of AIDS; and information on its transmission, the human immunodeficiency virus (HIV) antibody test, life-styles conducive to AIDS transmission, and therapies and medical treatments. The fourth chapter contains eight exercises that have been developed and pilot-tested with more than 200 participants in Learning about AIDS courses in England. Included is information on time and resources needed, instructions on how to run the exercises, and advice on how to handle specific student responses the exercises are likely to elicit. The fifth chapter offers guidelines for developing and evaluating these and other learner-centered materials. The sixth chapter lists printed and human resources available in England. A 1988 statistical update is appended. (CML)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED311158

PARTICIPATORY HEALTH EDUCATION STRATEGIES FOR HEALTH EDUCATORS WITH A RESPONSIBILITY FOR ADULT EDUCATION ABOUT AIDS.

INTERIM MATERIALS

Prepared by Hilary Homans, Peter Aggleton & Ian Warwick

Faculty of Education & Community Studies
Bristol Polytechnic

A project funded by AVERT in collaboration with the HEALTH EDUCATION AUTHORITY

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL IN MICROFICHE ONLY HAS BEEN GRANTED BY

A Kanatos

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

LEARNING about AIDS

CE052888

BEST COPY AVAILABLE

Acknowledgements

We are grateful to acknowledge the following for their help in the preparation of these interim **Learning about AIDS** strategies and materials: Annabel Kanabus of AVERT (AIDS Virus Education and Research Trust); Jane Randell, Sue Steel and Zarrina Kurtz of the HEA (Health Education Authority); Liz White of the Department of Education, Bristol Polytechnic.

Published by the Health Education Authority in association with AVERT.

Health Education Authority
78 New Oxford Street
London WC1A 1AH

AVERT
PO Box 91
Horsham
West Sussex RH13 7YR
Tel 0403 864010

Design: Bud Murryweather

© Avert/Health Education Authority, Hilary Homans, Peter Aggleton, Ian Warwick, 1987

ISBN 0-903652-19-6

Printed by Brandprint 5M & 3M 6/87

Reproduction Rights
Sections 3 and 4 may be photocopied for educational purposes though not for hiring out or re-sale by way of trade.

Contents

1	Introducing **Learning about AIDS**	5
2	The rationale for participatory approaches to AIDS education	9
3	Information for health educators using the **Learning about AIDS** package	15
4	Strategies and materials	35
5	Guidelines for evaluating and developing participatory approaches to AIDS education	67
6	Resources	71

1 INTRODUCING Learning about AIDS

OUR AIMS

There are many ways of helping people learn about AIDS. Some of these involve talks and lectures to provide people with the facts about the Acquired Immune Deficiency Syndrome – its nature, its origins and its causes. Others involve the use of films and videos which enable a wide range of information about the syndrome to be presented in a short space of time. Yet further approaches provide opportunities for people to explore their own anxieties about AIDS and to consider the implications of factual information for their own lifestyles and behaviour.

The **Learning about AIDS** project sponsored by AVERT (in collaboration with the Health Education Authority) is firmly located within the third of these paradigms. Its primary aim is to alert health educators[1] to some of the strategies they can use to develop more participatory approaches to AIDS education. It also seeks to identify some of the advantages of this form of learning in meeting the educational needs of client groups as diverse as health care professionals, social workers, youth, community and adult educators as well as teachers in schools and colleges.

The health education strategies and materials in this interim pack have been devised on the assumption that people already know a fair amount about AIDS. You have only to open a newspaper nowadays, switch on the television or radio, eavesdrop on a conversation in a cafe or pub, or take a walk down the street with your eyes on the bill boards around you to realise that, at least in one sense, AIDS has become a part of everyday life. Our own work developing and piloting the strategies and materials in this pack has confirmed such an impression. In another sense though, people are still very unsure about AIDS. Many continue to have anxieties about the ease with which the virus believed to cause AIDS can be transmitted. Others have difficulty differentiating between having been infected by this virus (being antibody positive to it) and having AIDS itself. Still others cling to the belief that only certain forms of sexual activity (anal intercourse for example) can spread AIDS. More alarmingly, it is still possible to hear people talking about gay men in Britain being the *cause* rather than the first *people to develop* AIDS.

Views like these continue to be expressed despite government sponsored public information campaigns and work by teachers, health education officers, voluntary sector workers and others to inform people about AIDS and how the virus is spread. If, in spite of this information, people are still confused, then questions need to be asked about the kinds of health education strategy that can help people cope with what in one sense they already know.

PARTICIPATORY APPROACHES TO HEALTH EDUCATION

Participatory approaches to health education have their origins in what people already know and feel about a particular issue. They value these understandings and emotional reactions, but use them as a starting point to explore the more rational responses that people can make. In AIDS education, participatory strategies are likely to recognise that people's perceptions of the epidemic as well as of the risks attached to particular behaviours will be influenced by at least three inter-related sets of factors.

[1] *Throughout these interim* **Learning about AIDS** *materials we use the term health educator in its broadest sense to describe someone who helps others learn about health, health issues and the social factors that affect health and well-being.*

- △ **Their perceptions of what causes health and illness in general**
- △ **Their perceptions of the lifestyles and behaviours (including sexual and drug-related lifestyles) that are likely to put people at risk of infection**
- △ **Their present knowledge about AIDS itself**

The **Learning about AIDS** project is concerned primarily with devising health education strategies and materials which take these issues seriously. The intention is to develop, pilot and disseminate participatory approaches to health education which will complement existing forms of provision which focus mainly on giving information.

USING Learning about AIDS MATERIALS

These interim **Learning about AIDS** materials have been produced to meet the immediate needs of health educators who want to use learner-centred approaches to AIDS education in their work. Their primary use will be in educating key personnel who themselves have a responsibility for helping others learn about AIDS.

> They are *not* intended for use in an unmodified form with members of the public, young people in schools or members of the client groups most affected by AIDS. Nevertheless, it is possible that the strategies suggested in these interim **Learning about AIDS** materials may stimulate the development of similar health education strategies to meet the needs of these groups.

Learning about AIDS strategies and materials can therefore be used by health education officers, health service trainers, teacher educators, local authority education advisers, social work trainers, private, public and voluntary sector training officers and others who have a responsibility for educating prospective AIDS educators.

Because participatory approaches to health education are non-didactic and because they encourage learners to ask questions, educators using **Learning about AIDS** will need to begin with a sound knowledge of the relevant issues. You won't be able to hand out **Learning about AIDS** exercises and hope that a group can just 'get on with it'. Many of the exercises in this pack begin by asking people to consider what they already know about AIDS. Opportunities are then provided for pooling this knowledge. But most importantly, time is put aside for clarification and reassurance by the health educator organising the session. Health educators using these materials will need to anticipate and respond effectively to the doubts and uncertainties that are expressed.

You may find it helpful to work your way through the following questions, so that you know where to begin in using these materials. Your answers will tell you which section of these materials to turn to next.

Making a start

1. Are you concerned with educating AIDS educators?

Yes . . . Go to Qu 2.	No . . . These materials are not suitable for your work in their present form.

2. Are you familiar with the rationale behind participative health education strategies?

Yes . . . You may find it interesting to read Section 2. Answer Qu 3.	No . . . You will need to read Section 2 of these materials to familiarise yourself with this. Then answer Qu 3.

3. Can you answer questions about statistics relating to AIDS?

Yes . . . You may find it interesting to read Section 3.1. Answer Qu 4.	No . . . You will need to read Section 3.1 and perhaps carry out some additional research of your own.

4. Can you deal effectively with questions about professional and medical explanations of AIDS?

Yes . . . You may find it interesting to read Section 3.2. Answer Qu 5.	No . . . You will need to read Section 3.2 and perhaps follow up some of the references in Section 6.

5. Can you deal effectively with questions about lay and popular explanations of AIDS ('AIDS is sent by God', 'AIDS is all around us', 'We've all got AIDS in us' etc.)

Yes . . . You may find it interesting to read Section 3.3. Answer Qu 6.	No . . . You will need to read Section 3.3 and perhaps follow up some of the references in Section 6.

6. Can you deal adequately with questions about the ways in which AIDS is transmitted?

Yes . . . You may find it interesting to read Section 3.4. Answer Qu 7.	No . . . You will need to read Section 3.4 and perhaps follow up some of the references in Section 6.

7. Can you deal effectively with questions about the HIV antibody test?

Yes . . . You may find it interesting to read Section 3.5. Answer Qu 8.	No . . . You will need to read Section 3.5 and perhaps follow up some of the references in Section 6.

8. Can you answer questions about the relationship between particular lifestyles (gay lifestyles, heterosexual lifestyles, drug-related lifestyles) and AIDS?

Yes . . . You may find it interesting to read Section 3.6. Answer Qu 9.	No . . . You will need to read Section 3.6 and perhaps follow up some of the references in Section 6.

9. Can you answer questions about therapies and medical treatments for people with AIDS?

Yes . . . You may find it interesting to read Section 3.7. Answer Qu 4.	No . . . You will need to read Section 3.7 and perhaps follow up some of the references in Section 6.

These interim **Learning about AIDS** strategies and materials have been extensively piloted with doctors, health visitors, general nurses, district nurses, community psychiatric nurses, adult, youth and community educators, students in teacher training and learners in adult education provision. They are undergoing constant development in preparation for the launch of the full **Learning about AIDS** programme in early 1988. The project team is keen to hear about your success in using and modifying these materials. Write to:

Hilary Homans & Peter Aggleton

Faculty of Education & Community Studies
Bristol Polytechnic
Redland Hill
BRISTOL BS6 6UZ

2 THE RATIONALE FOR PARTICIPATORY APPROACHES TO AIDS EDUCATION

THE BACKGROUND

It is increasingly recognised that Acquired Immune Deficiency Syndrome (AIDS) poses one of the greatest threats to public health that this century has known.[1] By the beginning of February 1987, 686 men and women in Britain had been reported with a diagnosis of AIDS and an estimated 50,000 others have been infected by Human Immunodeficiency Virus (HIV), the virus widely believed to be its cause. In the United States, some 30,000 people have currently been diagnosed with AIDS and an estimated 1½–2 million others have been infected (February 1987). In Central African countries such as Zaire, Uganda and Zambia, it has been estimated that some 5–10% of the population has already been infected (Institute of Medicine, National Academy of Sciences, 1986).

As yet there is no vaccine to protect people against AIDS. Nor is there any cure for the syndrome itself which results from profound damage to the immune system. While there are therapies and treatments for many of the life-threatening infections which follow this damage, there are currently no medical interventions which can rid the person of their underlying immune deficiency.

Against this background, health education has been widely identified as the most effective means of restricting the further spread of AIDS, and health educators have begun to consider the types of interventions they can make in responding to the challenges posed by the epidemic.

STYLES OF HEALTH EDUCATION

There are many ways in which health education can be carried out. Some approaches emphasise the value of information-giving as a way of bringing about behavioural change. Others argue that health education should seek to facilitate self-empowerment by providing opportunities for people to consider the ways in which their emotions and anxieties may prevent them from acting rationally on the basis of the information they have. Yet other health education strategies argue that attention should be focussed on the ways in which organisations and communities can be changed to help individuals make healthy choices. Finally, there are approaches to health education which argue that aspects of society must be restructured if people are to lead healthier lives.

These four different styles of health education can be called *information-giving, self-empowerment, community-oriented* and *socially transformatory* models of health education. These four models can be distinguished from one another in terms of the goals they set for health education intervention (Figure 1). They are described in more detail in Aggleton & Homans (1987).

[1] *In at least 50% of currently recorded cases, AIDS has proved to be fatal*

FIGURE 1

Model of health education	Goals associated with that model
Information-giving	To bring about particular changes in people's behaviour through information-giving
Self-empowerment	To enhance people's abilities to act rationally and to help people establish personal control over their lives
Community-oriented	To bring about changes within organisations and communities so that healthier choices can be made
Socially transformatory	To change the structure of society so that inequalities in health no longer exist.

THE INFORMATION-GIVING MODEL OF HEALTH EDUCATION AND AIDS EDUCATION

Of these four models, there is little doubt that the first has been the one most widely adopted in the field of AIDS education. In its own programmes of health education, the Department of Health for example has felt it important to alert people to the facts about AIDS – its signs and symptoms as well as the ways in which it can be transmitted. In early 1986, the first government public information campaign was launched costing £2½ million, and a Health Education Council booklet *AIDS: What Everybody Needs to Know* was made available to those requesting it. In November 1986, a further £20 million programme of public information was announced. A leaflet explaining how AIDS is transmitted has been sent to every household in the country and newspapers, road-side posters, cinema, television and radio are being used to promote messages such as 'AIDS: don't die of ignorance', 'AIDS is not prejudiced: it can kill anyone' and 'The longer you believe AIDS only infects others, the faster it'll spread'.

A number of initiatives in schools and colleges as well as in health and social services provision have also aimed to tell people more about AIDS. Some authorities have organised half or whole day programmes on 'AIDS Awareness'. Others have arranged conferences where information about AIDS has been given by physicians, health education officers and other experts. Yet others have shown films and videos to their employees and client groups. These may have been followed by group discussion of the relevant issues. Finally, there are institutions and authorities whose response has simply been to make posters and leaflets more readily available. Thus in health service provision, leaflets about AIDS have been distributed with salary and pay slips, and in schools, colleges and community education centres, posters have been placed in high access areas and leaflets have been left lying in libraries, common rooms and other shared facilities.

The belief that people will act rationally and sensibly on the basis of the information they receive is implicit in health education strategies such as these. However, there are many reasons for being sceptical about the likely success of health education interventions which rely on information-giving alone as a means of changing people's behaviour.

Although information-giving strategies have been widely used in tobacco, drugs and alcohol education, there is little evidence that they produce immediate or lasting effects (Gatherer et al, 1979). Health education messages are not uniformly received by those at whom they are directed. People actively work on the information they receive via a particular health education campaign – reinterpreting this to suit their own needs. Thus, although a person may be aware of the dangers of tobacco use, she or he may persist in smoking forty cigarettes a day because of the knowledge that not *all* smokers die of lung cancer. Similarly, knowing the dangers associated with excessive alcohol consumption is often far from sufficient to bring about a reduction in alcohol intake.

Of particular importance in determining how people respond to official health

education messages are popular or lay beliefs about health (Helman, 1978; Fitzpatrick, 1984; Herzlich & Pierret, 1986; Kleinman, 1986; Unschuld, 1986). These can seriously distort or disorient the impact of a health education initiative. For example, the lay belief that whether or not you are likely to catch a disease depends on the strength of your constitution (after all, 'Those who are fit never become ill, whereas those who are sickly are always doing so') can seriously distort how people respond to a campaign which emphasises that everyone may be at risk from a particular infection. Similarly, the lay health belief that whether or not a person contracts an infection depends on luck or chance (after all, 'Everyone is exposed to germs but only a few people catch them') can disorient the way in which people respond to a health education strategy which seeks to link specific behaviours to the risk of infection.

Health educators ignore the influence of lay health beliefs like these at their peril, since they powerfully influence the impact of professional health education messages. There is little reason to suppose that people will always act rationally and sensibly on the basis of the health-related information they receive. Effective programmes of health education need to complement information-giving with other strategies if they are to bring about enduring changes in attitudes and behaviours.

This is not to suggest that information-giving is an ineffectual health education strategy. Evidence suggests that information about a particular health issue can bring about changes in behaviour. This is especially true when the information is presented in a relevant way (preferably through word of mouth or personal contact) and when it is linked to discrete and specific behavioural changes (Gatherer et al, 1979; WHO, 1986). We would, however, caution against the widespread use of health education strategies which assume that information-giving by itself will bring about clear-cut changes in behaviour.

So how can health educators complement the existing range of information-giving initiatives in the field of AIDS education?

ALTERNATIVE STRATEGIES FOR AIDS EDUCATION

Earlier, we identified three alternative approaches to health education which do not have information-giving as their central focus. We called these the *self-empowerment*, the *community-oriented* and the *socially transformatory* models of health education. These three models differ from more mainstream approaches to health education in that they take their starting point from what people already know about a particular health issue – no matter how incomplete or partial this knowledge may be.

While self-empowerment, community-oriented and socially transformatory models of health education differ in terms of their goals, they all advocate the use of *participative* learning strategies. Self-empowerment models do so because they argue that if individuals are to gain greater personal control over their health, they must first explore the extent to which their anxieties and feelings about a particular issue prevent them from acting rationally. Whilst community-oriented and socially transformatory models also differ from one another in terms of their goals, they too argue that health education initiatives should begin with the shared experiences of particular client groups. Health education interventions which enable these collective understandings to be identified can therefore be the starting point for social change at an organisational, community or societal level.

Ultimately health educators and their clients will have to decide on the goals that are to be pursued within the context of a particular health education initiative. As educators committed to participatory approaches to learning, we can only sketch out some of the possibilities associated with the use of this alternative approach to health education. Nevertheless, it is possible to identify in general terms the advantages of participative AIDS education strategies (Figure 2).

FIGURE 2

Participatory approaches to AIDS education are likely to

- △ **Allow people the chance to identify their anxieties about the causes of health and illness in general**
- △ **Allow people the chance to explore their anxieties about the causes of AIDS in particular**
- △ **Allow people to consider the extent to which lay theories of health and illness have a basis in fact**
- △ **Allow people the chance to identify and reflect upon their perceptions of lifestyles different from their own**
- △ **Allow people the chance to consider the implications of health-related messages about AIDS for their own lifestyles**
- △ **Allow people the chance to consider the implications of health-related messages about AIDS for their own work practices**
- △ **Allow people to identify collectively the sorts of contributions they can make at home, at work and in the community to effective education about AIDS.**

Although most health education initiatives relating to AIDS have operated within a commitment to information-giving, it is possible to identify educational interventions within each of the three alternative models.

Within the context of AIDS education, *self-empowerment* models have been widely advocated by writers such as Spence (1986) and Tatchell (1986) whose self-help guides for those with HIV infection and/or AIDS have done much to encourage the development of more positive mental attitudes to fighting the disease. Workshop activities informed by self-empowerment principles have also been organised by many voluntary sector organisations working to provide support for those with HIV infection and/or AIDS.

Community-oriented models, on the other hand, have informed the work of self-help organisations such as the Terrence Higgins Trust, Body Positive and other voluntary groups. Founded originally within the gay community to provide information, education, counselling and support for gay men, the Terrence Higgins Trust has greatly extended the scope of its activities in recent months. These now include service provision for groups such as intravenous drug users, women and church-goers. The work of organisations such as these is similar to that of equivalent bodies in the United States where the success of community-oriented self-help groups in providing realistic and appropriate information on 'safer' sex has been widely recognised as a significant factor in slowing down the rate of transmission of HIV amongst gay men.

So far there have been few AIDS-related health education initiatives concerned with *social transformation*. Nevertheless, it is possible to identify the beginnings of these in demands for more government sponsored research into vaccines and therapies for AIDS (instead of leaving research of this kind up to the major pharmaceutical companies), a closer monitoring of popular press reporting of AIDS and an extension of welfare and disability rights for those with HIV infection and/or AIDS.

References

Aggleton, P. & Homans, H. (1987) *Educating about AIDS: a discussion document for Health Education Officers, Community Physicians et al with a responsibility for effective education about AIDS*. National Health Service Training Authority.

Fitzpatrick, R. (1984) Lay Concepts of Illness. In R. Fitzpatrick et al (eds.) *The Experience of Illness*. London, Tavistock.

Gatherer, A. et al (1979) *Is Health Education Effective?* Research Monograph No. 2. London, Health Education Council.

Herzlich, C. & Pierret, J. (1986) Illness: From Causes to Meaning. In C. Currer & M. Stacey (eds.) *Concepts of Health, Illness and Disease*. Leamington Spa, Berg.

Institute of Medicine, National Academy of Sciences (1986) *Mobilizing Against AIDS*. London, Harvard University Press.

Kleinman, A. (1976) Concepts and a Model for the Comparison of Medical Systems as Cultural Systems. In C. Currer & M. Stacey (eds.) *Concepts of Health, Illness and Disease*. Leamington Spa, Berg. (published 1986)

Spence, C. (1986) *AIDS: Time to Reclaim our Power*. London, Lifestory.

Tatchell, P. (1986) *AIDS: A Guide to Survival*. London, Gay Men's Press.

Unschuld, P. (1986) The Conceptual Determination of Individual and Collective Experiences of Illness. In C. Currer & M. Stacey (eds.) *Concepts of Health, Illness and Disease*. Leamington Spa, Berg.

WHO (1986) Report of a meeting on educational strategies for the prevention and control of AIDS. Geneva, 17–19th June, AIDS/CPA, 86, 4.

3 INFORMATION FOR AIDS EDUCATORS

In order to use participatory approaches to health education, health educators need to have a good knowledge of the issues they wish to explore with client groups. In Section 3 of these interim **Learning about AIDS** materials, we will try to identify some of the issues which health educators should know about if they are to use the participatory strategies in Section 4 effectively. In the space available, our treatment of these issues can not be complete. Nor are we claiming that there are only seven aspects of AIDS which need to be known about before participatory AIDS-education strategies can be used effectively. We would particularly welcome health educators' comments on the usefulness (or otherwise) of this section.

3.1 Statistics relating to AIDS

3.2 Professional and medical explanations of AIDS

3.3 Lay explanations of AIDS

3.4 Transmission

3.5 The HIV antibody test

3.6 Lifestyles and AIDS

3.7 Therapies and medical treatments

3.1 STATISTICS RELATING TO AIDS

As someone working in AIDS education, you are likely to be asked regularly for statistics relating to AIDS and Human Immunodeficiency Virus (HIV) infection. In England, Wales and Northern Ireland, these are produced regularly by the Public Health Laboratory Services (PHLS), Communicable Diseases Surveillance Centre, 61 Colindale Avenue, London NW9 5EQ. District Health Authorities should have copies of the weekly *Communicable Diseases Report* produced by this centre.

The figures below relating to HIV antibody positive persons are cumulative totals to the end of February 1987 and identify those who had *actually been tested for* antibodies to the virus. It is estimated that between ten and fifteen times this number of people are actually infected, many of whom are unaware of the fact.

It is interesting to note that in England, Wales and Northern Ireland only 2.8% of those with AIDS and 4.7% of those who are HIV antibody positive are women. In contrast, of the 1100 HIV antibody positive persons reported in Scotland, just over a quarter (293) were women. In Scotland, 60% of HIV antibody positive persons were intravenous drug users and only 15% were homosexual or bisexual men.

The statistics relating to cases of AIDS (Table 4) are for the UK as a whole and are cumulative totals to the end of March 1987, whereas those relating to HIV infection relate only to England, Wales and Northern Ireland. We have also included a total of recent American statistics since you may be asked questions about these.

TABLE 1

Cumulative totals of HIV antibody positive persons reported, by age and sex, to end February 1987

Age (years)	Male	Female	Unknown	Total
0–4	15	4	1	20
5–9	41	—	—	41
10–14	56	—	—	56
15–24	652	65	2	719
25–44	1859	90	6	1955
45–64	314	5	—	319
>65	24	3	1	28
Not stated	996	28	20	1044
Totals	3957	195	30	4182

TABLE 2

Cumulative totals of HIV antibody positive persons reported, by transmission characteristic, to end February 1987

Transmission characteristic	Male	Female	Unknown	Total
Homosexual/bisexual	2158	—	—	2158
Intravenous drug abuser (IVDA)	163	85	4	252
Homosexual & IVDA	24	—	—	24
Haemophiliac	941	2	1	944
Recipient of blood	20	12	—	32
Heterosexual	63	71	1	135
Child of HIV antibody positive mother	5	4	1	10
Several risks	4	—	—	4
No information	579	21	23	623
Totals	3957	195	30	4182

TABLE 3

Cumulative totals of reports of HIV antibody positive persons reported, by region, to end February 1987

Region	Cumulative totals	Region	Cumulative totals
ENGLAND		ENGLAND (cont'd)	
Northern	212	Wessex	164
Yorkshire	194	Oxford	232
Trent	175	S Western	124
E Anglia	121	W Midlands	267
NW Thames	1361	Mersey	66
NE Thames	453	N Western	86
SE Thames	538	WALES	42
SW Thames	111	NORTHERN IRELAND	36
Total			4182

TABLE 4

Cumulative totals of UK reports of AIDS cases, by transmission characteristic, to end March 1987

Transmission characteristic	Number of cases Male	Female	Total	Number of deaths
Homosexual/bisexual	640	—	640	342
Intravenous drug abuser (IVDA)	8	2	10	5
Homosexual & IVDA	7	—	7	4
Haemophiliac	31	—	31	23
Recipient of blood: abroad	4	4	8	6
UK	3	2	5	5
Heterosexual: presumed infected abroad	13	7	20	11
presumed infected in UK	1	4	5	4
Child of HIV antibody positive mother	3	4	7	4
Other	—	1	1	1
Totals	710	24	734	405

Source: *Communicable Disease Reports 87/09 and 87/13* (Tables 1–4)

TABLE 5

United States AIDS statistics

28,523 and counting . . .

AIDS Cases as Reported by the CDC as of December 15, 1986

Residence of Cases	Number of Cases	Residence of Cases	Number of Cases
New York State	8963	South Carolina	104
New York City	8218	Hawaii	101
California	6390	Tennessee	98
San Francisco	2911	Wisconsin	77
Los Angeles	2386	Oklahoma	76
Washington, D.C. (Metro Area)	787	Alabama	70
Florida	1911	Nevada	63
Miami	856	Kentucky	59
New Jersey	1717	Kansas	52
Newark	712	Utah	49
Texas	1712	Rhode Island	48
Illinois	714	New Mexico	41
Pennsylvania	648	Arkansas	40
Massachusetts	577	Delaware	40
Georgia	553	Mississippi	36
District of Columbia	509	Iowa	35
Maryland	416	Maine	32
Washington	337	New Hampshire	23
Connecticut	330	Nebraska	21
Virginia	329	Alaska	20
Louisiana	325	West Virginia	20
Puerto Rico	313	Vermont	9
Colorado	281	Virgin Islands	7
Michigan	246	Idaho	6
Ohio	246	Montana	6
North Carolina	169	Wyoming	5
Arizona	159	North Dakota	4
Missouri	158	South Dakota	3
Minnesota	146	Guam	1
Indiana	114	Trust Territory	1
Oregon	113	Pediatric Cases (included in above)	399

Of these, 16,128 (approximately 57%) are dead

Source: *New York Native*, 29th December 1986 (Compiled from Center for Disease Control Statistics)

3.2 PROFESSIONAL AND MEDICAL EXPLANATIONS OF AIDS

In this section we will begin by defining AIDS. We will then consider some of the different medical explanations offered. It is important for health educators to realise that amongst doctors and other health professionals there is rarely universal agreement about the causes of a particular illness or disease. This is particularly true of AIDS where currently there are a number of *competing* medical explanations about its cause.

What is AIDS?

According to the Center for Disease Control in Atlanta, Georgia (CDC, 1985) Acquired Immune Deficiency Syndrome (AIDS) is an illness sometimes diagnosed after a person has been infected by Human Immunodeficiency Virus (HIV). It is diagnosed by the *presence* of one of a limited number of diseases which do not normally attack people whose immune systems are working effectively, in the *absence* of all other known underlying causes of immune deficiency (such as drugs which suppress the immune system). Thus, if a person receiving immune-suppressive medication contracts one of these diseases, they will not be diagnosed as having AIDS. But if someone with HIV infection (and no other causes of immune suppression) does so, then they will be diagnosed as having AIDS. These diseases are often called *opportunistic* diseases since they attack the person because of the opportunity which their immune suppression provides.

The opportunistic diseases can be grouped chiefly into infections and tumours. The infection that has been most closely associated with AIDS is Pneumocystis carinii pneumonia (PCP), caused by a pathogen that occurs widely and only takes serious hold in people whose immune systems are not working properly. People with AIDS characteristically suffer also from thrush around the mouth and anus, and the whole gut may become colonized by the yeast (Candida) that causes thrush. Herpes simplex infection is common in people with AIDS, and other infections include Cytomegalovirus (CMV), Toxoplasma, and a protozoal infection – Cryptoccosis – which causes profuse and persistent diarrhoea. Infection with any of the variety of organisms that occur in people with AIDS tends to become widely spread throughout the body, whereas in other people these infections tend to remain localized and to clear up quickly.

The tumours that occur in AIDS are chiefly Kaposi's Sarcoma, a normally rare type of skin cancer that, once again in AIDS becomes widespread in the body, and Lymphomas.

HIV is now known to infect directly cells in the brain, the gut and the lungs, and to lead to disease in these organs. A number of those infected have died from acute meningitis and encephalopathy before any opportunistic infection or tumours have become manifest. In the longer term, brain disease leading to dementia has developed. A complete list of the opportunistic diseases associated with AIDS can be found in the book *Mobilizing against AIDS* (Institute of Medicine, National Academy of Science, 1986).

Whilst many of the opportunistic diseases associated with AIDS can be treated using conventional medical therapies (for example, PCP initially responds well to treatment with high doses of the drug co-trimoxazole (Septrin) and CMV infection can now be treated with a new drug called DHPG), attempts to treat the underlying immune deficiency have so far met with little success (but see also Section 3.5).

Other consequences of HIV infection

Contrary to popular belief and inaccurate reporting in the popular press, being infected by HIV (being HIV antibody positive) is *not* the same thing as having AIDS. As well as having HIV infection, a person must develop an opportunistic disease to be diagnosed with AIDS. This affects about 15–20% of people who have *had* HIV infection for three years (Scott, 1987). About a further 30–40% of people infected with HIV for three years develop mild symptoms such as persistently swollen glands (Persistent Generalised Lymphadenopathy or PGL), fever, sweats, aches, fatigue, unexplained weight loss, sickness and diarrhoea (New Scientist, March 1987). The term AIDS-Related Complex or ARC is used to describe this set of combined symptoms.

What causes AIDS?

The CDC's current definition of AIDS makes reference to the consequences of HIV infection. Whilst most doctors today believe that HIV is the cause of AIDS, this has not always been the case. Before HIV was isolated in 1983/4, at least four major theories about AIDS were popular (Figure 3).

FIGURE 3 Early professional and medical theories (pre 1983/4)

1. **AIDS is caused by immune system overload.**
2. **AIDS is caused by an already identified virus.**
3. **AIDS is caused by a new virus.**
4. **AIDS is caused by a coincidence of factors.**

The first of these early explanations suggested that AIDS was caused through repeated infection by sexually transmitted diseases and by the excessive use of recreational drugs such as Amyl and Butyl nitrite, Amphetamines etc. The second explanation, which proposed that AIDS was a consequence of Hepatitis B, Cytomegalovirus or Epstein Barr Virus infection, was put forward because the first cases of AIDS in the United States were seen amongst gay men and intravenous drug users – people specially at risk of infection by these viruses. The third explanation was in many ways a forerunner of more modern understandings of the syndrome, since it suggested that AIDS was caused by a new virus. The fourth argued that a combination of factors was needed to produce AIDS. These were said to include immune overload and the re-activation of previous Cytomegalovirus, Herpes, and Epstein Barr virus infections. An extremely readable account of these early theories can be found in Johnson and Ho (1985).

In 1983, a team of researchers working in Paris at the Pasteur Institute identified a new but special kind of virus in tissue from a gay man with swollen lymph glands. They called this virus Lymphadenopathy Virus (LAV). Shortly afterwards in 1984, another research team working in the United States isolated a similar (if not identical) virus from people with AIDS. They called their virus Human T-cell Lymphotropic Virus Type III (HTLV-III). In order to resolve the problem of terminology, it has subsequently been agreed that the virus should be renamed Human Immunodeficiency Virus (HIV). Since the identification of this virus, medical explanations have shifted quite a lot. There are now three major professional explanations of AIDS (Figure 4).

FIGURE 4 Later professional and medical explanations of AIDS (after 1983/4)

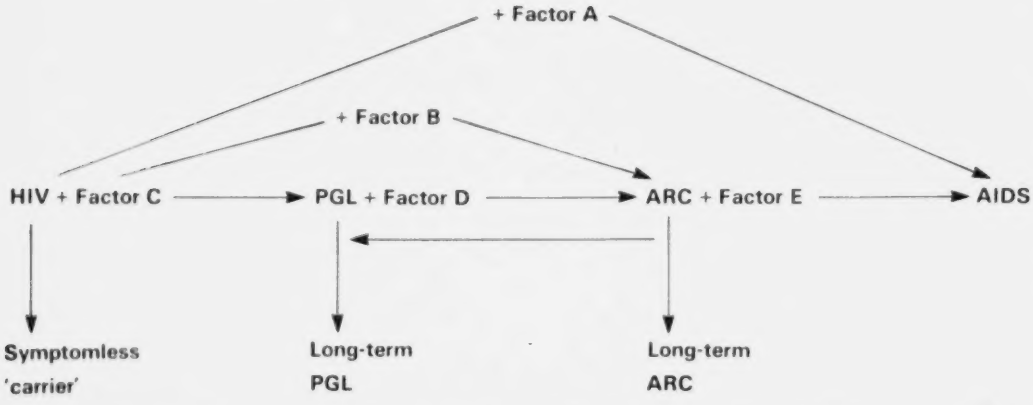
1. **Infection by HIV is necessary and sufficient to cause AIDS.**
2. **Infection by HIV is necessary but *not* sufficient to cause AIDS.**
3. **Infection by HIV is a marker of infection by an as yet unidentified 'true' cause of AIDS.**

The first of these modern explanations (Figure 5) implies that infection by HIV is all that is needed for a person to develop AIDS subsequently. Whilst it acknowledges that there can be many consequences of HIV infection, it suggests that progression between these is likely to take place more or less irrespective of what a person does.

FIGURE 5 HIV as a necessary and sufficient cause of AIDS

The second explanation (Figure 6) argues that co-factors (perhaps other infections, other life events or factors to do with a person's lifestyle) may be needed for a person to develop AIDS. There is good evidence to support this interpretation among some HIV infected people. For example, infection by other sexually transmitted diseases may increase the likelihood of HIV infection progressing to AIDS (Weber et al, 1986), and pregnancy in a woman who is HIV positive may increase her risk of subsequently developing AIDS (Pinching & Jeffries, 1985).

FIGURE 6 HIV as a necessary but not sufficient cause of AIDS



The third explanation, which argues that HIV is itself an opportunistic infection which attacks people who are already immune compromised, is most closely connected with the view that an unidentified virus may be the real cause of AIDS. Candidates for such a virus include African Swine Fever virus (which causes fever, enlarged lymph nodes, skin lesions, immune modulated pneumonia and brain disease in affected pigs; Beldekas et al, 1986) and a new un-named virus recently isolated from people with AIDS (Lo, 1986). There is very little medical support for this explanation, although theories of this type are widely known about within the gay community.

Of course it is also possible that the explanations offered so far, will not provide a

complete understanding of AIDS. Effective programmes of health education will need to identify ways of helping people cope with this uncertainty.

Origins

Although people rarely pause to consider where the virus responsible for the common cold (or Herpes for that matter) originally came from, there is considerable interest in identifying the origins of HIV. AIDS educators will need to be aware that there are a number of theories concerning the origins of this virus. First, it has been suggested that the virus originated in Africa. Evidence for this claim comes from studies which have identified the presence of viral infection similar to that produced by HIV amongst wild African green monkeys. A virus called STLV-III (S stands for Simian) has been isolated from some of these animals. STLV-III shares some genetic similarities with HIV. Normally however viruses which cause diseases in animals do not affect humans, so these observations do not necessarily explain how AIDS came to be so prevalent in Central Africa (let alone in New York, San Francisco and Miami!).

Other explanations on the origins of AIDS include a suggestion that the virus may have been genetically engineered, perhaps within the context of biological warfare – some versions of this theory blame the CIA, others the KGB. Another theory popularised by the astronomer Fred Hoyle suggests that the virus may have arrived in meteorites from outer space.

There is little or no concrete evidence to support either of these claims, and in entertaining suggestions like these, we are beginning to move rapidly from professional to lay explanations of AIDS. In Section 3.3 we will look at some of these more closely.

References

Beldekas, J. et al (1986) African Swine Fever Virus and AIDS. *Lancet*, 8th March, pp.564–5.

CDC (1985) Current CDC Definition of AIDS. In Institute of Medicine, National Academy of Sciences, *Mobilizing against AIDS: The Unfinished Story of a Virus*. London, Harvard University Press.

Institute of Medicine, National Academy of Sciences (1986) *Mobilizing against AIDS: The Unfinished Story of a Virus*. London, Harvard University Press.

Johnson, E. & Ho, P. (1985) The Elusive Etiology – Possible Causes and Pathogenesis of AIDS. In V. Gong (ed.) *Understanding AIDS*. Cambridge, Cambridge University Press.

Lo, S. (1986) Isolation and identification of a novel virus from patients with AIDS. *American Journal of Tropical Medicine and Hygiene*, 35, 4, pp.675–6.

New Scientist AIDS Briefing (1987) How the course of the disease varies. *New Scientist*, 1553, p.36.

Pinching, A. & Jeffries, D. (1985) AIDS and HTLV-III/LAV Infection: Consequences for obstetrics and perinatal medicine. *British Journal of Obstetrics and Gynaecology*, 92, pp.1211–1217.

Scott, A. (1987) Tests to detect infection. *New Scientist*, 1553, p.37.

Weber, J. et al (1986) Factors affecting seropositivity to HTLV-III/LAV and progression of the disease in partners of patients with AIDS. *Lancet*, 14th May, pp.1179–1181.

20

3.3 LAY EXPLANATIONS OF AIDS

Research into lay explanations

Medical and professional understandings of a disease such as AIDS co-exist alongside more popular or lay understandings of the same phenomenon. Whilst research into lay perceptions of AIDS is in its infancy, there are a number of research projects currently under way which will shed light on these. First, there is our own study of young people's health knowledge and AIDS.[1] Then there are two longitudinal studies of patterns of sexual behaviour being carried out by Coxon,[2] a behavioural study of gay men by Boulton, Fitzpatrick and Hart[3] and an anthropological study of prostitution in north London being carried out by Day[4]. Whilst the first of these studies is the only one to address directly popular perceptions of AIDS itself, the others may add to our knowledge of lay understandings of the syndrome via their attempts to explore different client groups' perceptions of risk. A more extended discussion of lay perceptions of AIDS and their implications for effective programmes of health education can be found in Aggleton & Homans (1987).

Explanations

It is currently possible to identify at least four different kinds of lay theories about AIDS (Figure 7).

FIGURE 7 Lay theories about AIDS

1. **AIDS is caused by something in the person (Endogenous theories)**
2. **AIDS is caused by something outside or around the person (Exogenous theories)**
3. **AIDS is caused by 'irresponsible' behaviour (Personal responsibility theories)**
4. **AIDS is caused by divine retribution (Retributionist theories)**

[1] **Young People's Health Knowledge and AIDS**

Project Directors: *Dr Peter Aggleton*
Dr Hilary Homans

Faculty of Education & Community Studies
Bristol Polytechnic
Redland Hill
BRISTOL BS6 6UZ

[2] **A Longitudinal study of the sexual behaviour of homosexual men and the impact of AIDS**

A Longitudinal study of the sexual behaviour of non-homosexual men and the sero prevalence of HIV

Project Director: *Professor A Coxon*

Department of Sociology
University College Cardiff
PO Box 78
CARDIFF CF1 1XL

[3] **Health beliefs and the behaviour of homosexual men**

Project Directors: *Dr Mary Boulton*
Mr Ray Fitzpatrick
Dr Graham Hart

St Mary's Hospital Medical School
St Mary's Hospital
Praed Street
LONDON W2 1PG

[4] **A social anthropology of female prostitutes in London**

Project Contact: *Dr Sophie Day*

Dept Genito-Urinary Medicine
St Mary's Hospital
Praed Street
LONDON W2 1PG

Endogenous theories

These suggest AIDS is caused not by a virus but by some quality of the individual. Thus, in Vass's (1986) study of public opinion and AIDS, it was found that 44% of the respondents questioned felt that homosexuality was the cause of AIDS. Only 14% of those interviewed identified a viral cause for the syndrome. Lay theories like this are significant because they suggest that a person's perception of whether or not they are at risk for AIDS may be influenced by whether or not they see themselves as gay.

An alternative endogenous explanation suggests that AIDS may already lurk within us all. Our own work associated with the project *Young People's Health Knowledge and AIDS* suggests that some people hold the belief that AIDS (like cancer, so our respondents suggest) lurks within us all, being something we are born with. All that is needed for it to appear is the right set of circumstances.

Exogenous theories

Exogenous theories on the other hand suggest that AIDS is caused by factors external to the individual. Some exogenous theories link closely to *miasmatic* beliefs about disease in general (Open University, 1985). These ancient ideas, which suggest that disease spreads like a mist or miasma through the air, continue to influence some people's desire to avoid persons or environments which they presume will increase the likelihood of their own infection. Some people seem to believe that AIDS is 'all around us' and that everyone, regardless of their behaviour, is currently at risk of infection.

Other exogenous lay theories suggest that AIDS has been triggered off by attempts to meddle with the environment. The testing of too many atomic weapons, the widespread introduction of atomic power as well as environmental pollution has created an ecological instability which has resulted in AIDS.

Personal responsibility theories

In discussing lay theories which link AIDS with personal responsibility, it is important to distinguish between the theories which individuals use to understand the events which befall others and those which they use to understand their own behaviour.

With respect to AIDS, lay theories of the former type frequently differentiate between 'innocent' and 'guilty' victims of the disease (Altman, 1986). This distinction differentiates between those whose behaviour somehow makes it 'reasonable' that they should have contracted AIDS and those who developed the syndrome through 'no fault of their own'. Within the former category, gay men, prostitutes, the promiscuous, bisexuals and intravenous drug users are usually placed. Within the latter category, haemophiliacs, blood transfusion recipients, children and the married partners of those who engage in extra-marital relationships are given prominence. Lay theories like this frequently inform media reporting of AIDS by the popular press.

When it comes to explaining what happens to the self, however, there is some evidence that people are more likely to act with *serendipitous* theories about the causes of infection. These suggest that whether or not one contracts HIV infection or AIDS depends largely on luck or chance. Our own research confirms that many young people believe that while there may be some point in trying to limit the risk of infection, whether or not one becomes infected ultimately depends on chance factors over which there can be little personal control.

Retributionist theories

Retributionist lay theories of disease suggest that actions which infringe supposedly fundamental moral values are likely to bring about divine retribution. The Black Death in fourteenth-century Europe was widely interpreted as a pestilence inflicted by God, and in Britain and the United States nowadays some fundamentalist religious commentators have suggested that AIDS may be divine retribution for the transgression of biblical proscriptions against homosexual behaviour.

Many of those who espouse these theories seem oblivious to the widespread incidence of AIDS amongst heterosexual adults in Africa (Biggar, 1986) and to the selective way in which Christian dogma has to be *interpreted* to support such claims (see for example, Boswell, 1980; Uhrig, 1986).

Nevertheless, by running contrary to both rational and empirical claims about AIDS, and by making recourse to supernatural modes of explanation, retributionist analyses such as these are likely to act as powerful filters of official health education messages.

References

Aggleton, P. & Homans, H. (1987) *Educating about AIDS: a discussion document for Health Education Officers, Community Physicians et al with a responsibility for effective education about AIDS*. National Health Service Training Authority.

Altman, D. (1986) *AIDS and the New Puritanism*. London, Pluto Press.

Biggar, R. (1986) The AIDS Problem in Africa. *Lancet*, 11th January, pp.79–82.

Boswell, J. (1980) *Christianity, Social Tolerance and Homosexuality*. Chicago, University of Chicago Press.

Open University (1985) *Health and Disease*, U205, Book 2. Milton Keynes, Open University Press.

Uhrig, L. (1986) *Sex Positive: A Gay Contribution to Sexual and Spiritual Union*. New York, Alyson Publications.

Vass, A. (1986) *A Plague in Us*. Cambridge, Venus Academica.

3.4 TRANSMISSION

Isolation and transmission

Isolation

In AIDS education, it is vitally important to help client groups differentiate between research into the body fluids and tissues from which HIV can be *isolated* and the body fluids and tissues through which it is *transmitted*.

Human Immunodeficiency Virus (HIV) has been *isolated* from many body fluids and tissues including:

- △ **blood**
- △ **vaginal and cervical secretions**
- △ **saliva**
- △ **semen**
- △ **breast milk**
- △ **tears**

However, it is important to realise that being able to isolate a micro-organism from a particular medium does *not* mean that it is necessarily transmitted in that way. For example, many potentially lethal micro-organisms can be grown under complex laboratory conditions from smears taken from table tops, work surfaces etc. This does not mean that these same micro-organisms are necessarily *transmitted* via these surfaces.

Transmission

In most cases, a critical quantity of a micro-organism (an inoculum) must pass via a critical route specific to that micro-organism in order for transmission to occur. Evidence of the ways in which HIV is *transmitted* comes largely from studies of three different types.

- △ **Epidemiological studies of those groups most affected by HIV infection**
- △ **Sexual contact studies**
- △ **Studies of households, hospitals and workplaces**

It does *not* come from studies of the body fluids from which HIV can be isolated.

How HIV is transmitted

Transmission studies demonstrate quite unequivocally that HIV can be transmitted via the following routes:

- △ **blood**
- △ **blood products**
- △ **semen**
- △ **vaginal and cervical secretions**
- △ **organ transplants**

HIV can be transmitted via vaginal intercourse without a condom from man to woman and from woman to man (Calabrese & Gopalakrishna, 1986; Fischi et al, 1987). Amongst gay men, anal intercourse without a condom is the activity which carries the greatest risk of transmitting HIV particularly to the receptive partner (Kingsley et al, 1987), and anal intercourse between a man and a woman may carry a similar risk. There is also some evidence suggesting that HIV can be transmitted via breast milk from mother to child.

How HIV is not transmitted

These same studies strongly suggest that HIV can *not* be transmitted via the following routes:

- △ touch
- △ bodily contact
- △ coughing and sneezing
- △ cups, cutlery and food
- △ swimming pools
- △ being in the same room as someone else
- △ towels
- △ toilet seats
- △ pets
- △ mosquitos and flying insects
- △ shared bathing and showering facilities
- △ drinking from the same glass

Whilst HIV has been isolated from tears and saliva under sophisticated laboratory conditions, there is *no* evidence for transmission by either of these routes. Indeed, recent research has shown that saliva contains at least two components which actually *inhibit* HIV (Fultz, 1986).

Likewise, there is *no* evidence whatsoever that HIV can be casually transmitted in households. In a recent study of 90 children of 45 People with AIDS (PWA), not one of the children was found to be infected by HIV in spite of the fact that they had regularly hugged and kissed their parents and had shared kitchen and bathroom facilities with them (Fischi et al, 1987). In this same study, not one of the 29 friends and relatives who lived with the PWA, and who were not involved sexually with them, became infected. Neither is there any evidence that HIV can be transmitted by close contact at the place of work. Indeed, even when health care workers have been accidentally and directly exposed to the virus, the chance of transmission is slight. Of 150 health care workers in the UK who were accidentally exposed to the blood or body fluids of patients infected with HIV, *not one* has sero-converted after a follow-up lasting twelve months (McEvoy & Porter, 1987). In the United States there have been only two documented cases of sero-conversion in health care workers following needlestick injuries. (A possible third case is suspected.) (Conte, 1986 and McCray et al, 1986).

Safer Sexual Practices

Given what we presently know about the ways in which HIV can be transmitted, it is possible to work out from first principles the sexual activities which are likely to be risky and those which are likely to be relatively safe.

Sexual activity (vaginal intercourse, anal intercourse, and probably to a much lesser extent, oral intercourse) which is likely to result in the transmission of semen or vaginal and cervical fluids from one person to another is *risky*. Sexual activity which breaks the skin or draws blood (either internally or externally) is also *risky*.

The risk of transmission is significantly reduced when precautions are taken to avoid one person's body fluids entering another individual. There are many forms of sexual expression which do not involve bodily penetration or the exchange of those body fluids which are known to transmit the virus. These include mutual masturbation and erotic massage.

Alternatively, the *proper use* of condoms can also reduce (but not eliminate) the risk of infection. These should be used with a water-based lubricant such as K-Y gel to minimise the likelihood of them tearing. Additionally, using condoms in conjunction with a spermicide containing the ingredient Nonoxynol 9 (which inactivates HIV under laboratory conditions, Hicks et al, 1985), may reduce the chance of transmission even further.

Other safer sexual options can include celibacy. The Terrence Higgins Trust produces some useful leaflets identifying safer forms of sexual expression.

Safer blood

Since October 1985, all blood donations in Britain have been routinely screened for antibody to HIV. Additionally, efforts have been made to ensure that blood is no longer taken from members of high risk groups. These combined efforts have ensured that there is a close to zero risk of infection from a blood transfusion. Nevertheless, because it can take some months for antibodies to develop in a person with HIV infection (see also Section 3.5),

the possibility of there being HIV contaminated blood cannot be entirely ruled out. Efforts are currently underway to develop cheap and effective tests which will enable blood to be screened for HIV itself rather than for HIV antibody. Of 2,577,417 blood donations tested by late 1986, 55 were found to contain antibodies to HIV and were discarded. In some parts of the world, blood is not routinely screened in this way, so those offered transfusions abroad will have to consider carefully the risks associated with these.

The blood products used by haemophiliacs are now heat-treated to render them safe. Heat treatment cannot, however, be used on whole blood.

Safer Drug-Related Practices

Because HIV can be transmitted via blood, there is a risk that those who use drugs intravenously and who share their syringes and needles (works) with others can pass the virus on via this route as well as by sexual contact. The Terrence Higgins Trust in conjunction with the Standing Conference on Drug Use (SCODA) has produced a booklet *Facts about AIDS for Drug Users* which identifies the steps that intravenous drug users can take to minimise the risk of becoming infected or infecting others (see Section 3.6).

References

Calabrese, L. & Gopalakrishna, K. (1986) Transmission of HTLV-III infection from a Man to Woman to Man. *New England Journal of Medicine*, 314, 15, p.987.

Conte, J. (1986) Infection with Human Immunodeficiency Virus in the Hospital. *Annals of Internal Medicine*, 105, pp.730–736.

Fischl, M. et al (1987) Evaluation of Heterosexual Partners, Children and Household Contacts of Adults with AIDS. *Journal of the American Medical Association*, 257, 5, pp.640–44.

Fultz, P. (1986) Components of Saliva Inactivate Human Immunodeficiency Virus. *Lancet*, 22nd November, p.1215.

Hicks, D. et al (1985) Inactivation of HTLV-III/LAV infected cultures of normal human lymphocytes by Nonoxynol 9 in vitro. *Lancet*, 21st December, p.1422.

Kingsley, L. et al (1987) Risk Factors for Seroconversion to Human Immunodeficiency Virus amongst Male Homosexuals. *Lancet*, 14th February, pp.345–349.

McCray, E. et al (1986) Occupational Risk of the Acquired Immunodeficiency Syndrome among Health Care Workers. *New England Journal of Medicine*, 314, 17, pp.1127–1132.

McEvoy, M. & Porter, K. (1987) Health care workers and the risk of HIV infection. *Lancet*, 24th January, p.224.

3.5 THE HIV ANTIBODY TEST

When someone is infected by a virus, their body normally makes antibodies to that virus. These antibodies usually neutralise the infection. After being infected by Human Immunodeficiency Virus (HIV) most people's bodies manufacture antibodies to the virus. These can be detected by means of an antibody test which will confirm whether the individual is *antibody positive* or *antibody negative*. However, there are some important differences between the antibodies which are produced to HIV and those that are produced in response to many other viral infections.

First, the antibodies which are manufactured to HIV do *not* neutralise the effects of the virus itself which means that people who are antibody positive are *not* immune to HIV, and are therefore at risk of the consequences of HIV infection. People who are antibody positive to the virus are likely to remain infectious for the rest of their lives.

Second, it can take several months for these antibodies to develop. In the majority of people they are present within three months of infection, but in a few cases they can take up to twelve months (or occasionally even longer than this) to appear. Because there is this delay or 'window' between infection and the production of antibodies, at any one moment there will be a small number of people who may be virus positive (that is, they are infected by the virus) but antibody negative. For this reason, a repeat antibody test is often given to people who have reason to believe they are at high risk of infection three to four months after the first.

HIV antibody tests are now widely available in clinics for the treatment of sexually transmitted diseases (Special Genito-Urinary Medicine Clinics or VD Clinics as they used to be called) and from many general practitioners. In order to carry out the test, a small sample of blood is taken from a vein in the arm. This blood is then sent away for testing and the result will usually be available in about two weeks. Pre-test and post-test counselling should be provided by the clinic or general practice where the test is carried out (Green, 1986; Green & Miller, 1986). However, it is only fair to say that currently there is considerable variation in the quality of the counselling people receive.

Before someone decides to have a test, there are many things to be considered. We can only list a few of them here. Further guidance on the HIV antibody test is given in the leaflet *HIV Antibody: To Test or Not to Test* available from the Terrence Higgins Trust (THT, 1986).

Things people will need to consider before having the HIV antibody test

- △ **The consequences of receiving a positive test result**
- △ **The consequences of receiving a negative test result**
- △ **Whether knowing their antibody status will improve their quality of life**
- △ **Whether a test result is really needed in order to take steps to adopt safer sexual and/or drug related practices**
- △ **The possible reaction of friends, colleagues and employers**
- △ **Whether the circumstances in which the test is carried out will provide an appropriate quality of service (including levels of pre and post test support, confidentiality, etc.).**

What the test shows someone

△ **Whether their body has made antibodies to HIV – implying that they have been infected by the virus.**

△ **Whether their body has not made antibodies to HIV – implying either that they have not been infected or that too short an interval has elapsed between infection and testing for detectable antibodies to be produced.**

It can take several months for antibodies to develop although they normally appear within three months of infection. Nevertheless, a few people may not produce antibodies until a year or so after infection.

△ **The test will *not* tell someone whether they will develop AIDS. 80–85% of those who are antibody positive do not develop AIDS in the three-year period following infection.**

References

Green, J. (1986) Counselling HTLV-III Sero-positives. In D. Miller et al. *The Management of AIDS Patients*. Basingstoke, Macmillan.

Green, J. & Miller, D. (1986) Hospital Counselling: Structure and Training. In D. Miller et al. *The Management of AIDS Patients*. Basingstoke, Macmillan.

THT (1986) *HIV Antibody: To Test or Not To Test?* London, Terrence Higgins Trust.

3.6 LIFESTYLES

Given what we currently know about HIV transmission and incidence it is assumed that certain lifestyles are implicated in the spread of the disease. The statistics up to the end of 1986 show that in England, Wales and Northern Ireland 51% of HIV antibody persons are homosexual/bisexual, 24% are haemophiliacs and 6% are intravenous (IV) drug users (Section 3.1, Table 2). Haemophiliacs have been exposed to the virus through contaminated Factor VIII blood products which they need regular access to, and the transmission in these instances can be seen as iatrogenic (medically induced) rather than as a result of the lifestyle of the haemophiliac. However, in relation to both sexual and IV transmission it is often argued that it is the *lifestyle* of the gay or bisexual man or IV drug user which increases their risk of coming into contact with the virus.

The argument which sees lifestyles as increasing the risk of transmission needs to be scrutinized in two respects. Firstly, the lifestyles of neither gay or bisexual men, nor drug users are homogenous, and secondly it is not a general lifestyle which is implicated in the transmission of HIV, but *particular acts*.

IV drug users

There appears to be considerable diversity of lifestyle amongst drug users, with people of varying social backgrounds using injectable drugs recreationally. This is contrary to the popular image of the IV drug user depicted in the 'Heroin screws you up' campaign. It is important that health educators do not allow their understanding of IV drug users' lifestyles to be restricted by popular stereotypes. As with most illegal behaviour it is difficult to gain an accurate picture of the kind of people who use drugs intravenously, and those who come to our attention tend to be encountering problems. We know very little for example about people who inject drugs whilst retaining a 'respectable' image. Recent evidence suggests that the recreational use of injectable drugs may form part of an upper-middle-class social scene.

As far as IV drug users and HIV infection are concerned it is not the use of the drug which is the problem (though using these drugs may have other health consequences). It is the particular act of injecting oneself using 'dirty' equipment, for example a needle which has been used before, which carries the risk. Health education campaigns aimed at risk reduction therefore stress the message that if you must inject, use clean equipment. The success of these campaigns should be apparent by the time we produce the full **Learning about AIDS** materials and we will be able to make reference to these together with the findings of research which is just about to begin into AIDS and IV drug users (Stimson).[1] You may be interested to get hold of *AIDS: How drug users can avoid it*, published by the Standing Conference on Drug Abuse (SCODA, 1986).

Gay sexual behaviour

Popular media reports portray the stereotypical gay lifestyle as extremely promiscuous and involving bizarre sexual behaviour. In many accounts it is this gay lifestyle which is seen as responsible for the spread of AIDS. Several points need to be clarified in relation to these beliefs which are held by both lay and professional people alike. Firstly, same sex behaviour and lifestyles are as diverse as heterosexual lifestyles. Secondly, it is not accurate to call AIDS a gay disease: lesbians are currently the group least likely to be at risk of HIV infection and AIDS. It is not therefore same sex lifestyles which are the cause of the disease, but particular forms of sexual acts (eg penetrative intercourse) which are most likely to facilitate transmission of the virus.

In the absence of national data on sexuality we do not have accurate information on the total number of people who are gay or lesbian, the number of people who have been involved in same sex or heterosexual activity, the numbers of sexual partners people have

[1] **IV drug use and AIDS**

Project Director *Dr G.V. Stimson*
Department of Sociology
Goldsmiths College
LONDON SE14 6NW

and so on. There are studies which go some way to providing this information, but many of them are riddled with methodological problems. For example, how do you go about obtaining a representative sample of gay men? Most studies of gay men obtain their samples through community networks and therefore do not include those who are not part of these networks. In terms of statistical information we are largely dependent on the work of Kinsey which was published as long ago as 1948. These findings showed that:

- △ **just under 40% of the male population had at least some same sex experience to the point of orgasm between adolescence and old age;**
- △ **about 30% of all males had been actively gay for a period of at least 3 years between the age of 16 and 55;**
- △ **about 6% of males were exclusively gay throughout their life.**

A more recent study of sexual behaviour in America (Hunt, 1974) supports the findings in the Kinsey report and argues that whilst a commitment to same sex relationships has become more visible, these relationships do not appear to have become more common.

There is clearly a difference between same sex acts, which may be isolated and related to particular social circumstances and same sex relationships. If we focus on studies of the lifestyles of men who define themselves as gay, then we find that these lifestyles are very diverse. Plummer's research (1978) into gay relationships has shown that there are as many variations in gay male couples as there are in heterosexual ones. He categorises gay relationships into same sex marriage, boyfriends and same sex partnership. Plummer refers to other studies which show that 40–60% of gay men do form stable relationships of over a year's duration, but also notes that very few of these relationships are likely to last more than 10 years. However as we said before, there are methodological problems in obtaining representative samples of gay men and those who are likely to be excluded from such studies are the long term committed couples and those who are celibate.

Media reports of male gay behaviour stress promiscuity, the frequency of sexual activity and the large numbers of sexual partners. Data collected based on interviews about sexual activity indicates that self-reports may not be entirely accurate (Coxon, 1986). The definition of 'sexual partner' may be loosely interpreted and vary from person to person. A sexual partner may therefore be defined by some to include kissing, and by others it may only include penetrative intercourse. The estimation of the total number of partners is often calculated in a way which tends to overestimate the actual total figure. For instance, in many cases the number of partners a person has in one week may simply be multiplied by 52 to indicate the number of partners annually. This form of calculation thus ignores those periods when the person is in a committed relationship and the number of partners is likely to be reduced.

The Spada Report (1979) of gay male sexuality provides evidence to contradict recent media reports of large numbers of sexual partners over a concentrated period of time as being the norm. The report is based on the experiences of 1038 gay men aged 16–77 and shows that 21% of men have sex once or twice a week; 17% three to four times a week; and 16% at least once a day. The remaining 45% have sex less frequently. These figures appear to be comparable with heterosexual frequency of sexual intercourse. What is most likely to be the case is that sexual activity is greater amongst people aged 17 to middle age *irrespective* of whether they engage in same-sex or heterosexual relationships. Also, sexual activity varies depending on where people live and the ease with which they can experiment sexually. Promiscuity is certainly not restricted to same-sex relationships, though a significant aspect of gay liberation involved challenging the norms perceived within stereotypical heterosexual marriage (Altman, 1983; Bronsky, 1984).

Neither are statistically infrequent sexual practices restricted to gay men. A recent study in *Forum* magazine (Coveney et al, 1984) of swinging and group sex amongst heterosexuals describes some of the bizarre sexual practices women are said to have experienced in response to pressure to experiment and be more sexually liberated.

Finally, in relation to AIDS, it is important to remember that it is *not* the number of sexual partners which puts a person at risk, but the nature of the sexual act that takes place between them. Mutual masturbation with no exchange of body fluids will not result in the virus being transmitted. Unprotected penetrative intercourse with *one* person who is infected is risky.

References

Altman, D. (1983) *The Homosexualisation of America*, New York, St. Martin's Press.

Bronsky, M. (1984) *Culture Clash: the Making of the Gay Sensibility*, Boston, South End Press.

Coveney, L. et al (1984) Theory into practice: sexual liberation or social control? (*Forum* magazine 1968–71) in Coveney, L. et al (eds.) *The Sexuality Papers: Male Sexuality and the Social Control of Women*, London, Hutchinson.

Coxon, T. (1986) *Gay male lifestyles*, paper given at the Social Aspects of AIDS Conference, Bristol Polytechnic, October.

Kinsey, A.C. et al (1948) *Sexual Behaviour in the Human Male*, Philadelphia, Saunders.

Hunt, M. (1974) *Sexual Behaviour in the 1970's*, Chicago, Playboy Press.

Plummer, K. (1978) 'Men in love: Observations on male homosexual couples', in Corbin, M. (ed) *The Couple*, Harmondsworth, Penguin Books Ltd.

SCODA (1986) *AIDS: How Drug Users Can Avoid It*, SCODA.

Spada, J. (1979) *The Spada Report: The Newest Survey of Gay Male Sexuality*, New York, Signet Book.

3.7 THERAPIES AND MEDICAL TREATMENTS

Drugs

Whilst there are therapies and medical interventions effective against many of the opportunistic diseases associated with AIDS, there are at present few effective interventions that can be undertaken with respect to the underlying immune deficiency itself. Generally speaking there are few drugs which are effective against viruses, and HIV poses special problems as far as drug therapy is concerned because in order to replicate it has to integrate itself into the host's own genetic makeup, and therefore drugs aimed at killing the virus may also kill vital host cells.

Nevertheless, a number of drugs have been identified which can slow down or, in a large enough dose, halt HIV replication. Most of these work by interfering with an enzyme (reverse transcriptase) which HIV needs to produce in order to replicate. Perhaps the best known of these drugs is Azidothymidine (AZT or Retrovir) produced by the drug company Wellcome. This has been shown to be effective in reducing the rate at which HIV replicates. It is currently undergoing clinical trials in Europe and the United States. Preliminary findings from these trials suggest that whilst the drug has side effects, it is often effective in preventing the recurrence of Pneumocystis carinii pneumonia. Some evidence also shows that it may be effective against the dementia which some PWA (people with AIDS) show.

Another drug, Ribavirin, has also been shown to be effective in slowing down HIV replication. This too is currently undergoing clinical trials in the United States. A number of substances considerably less toxic than AZT have been shown to halt viral replication under laboratory conditions, but these will require clinical evaluation before they can be said to be of practical use in AIDS therapy.

Vaccines

Until recently, it was believed that manufacturing a vaccine effective against HIV would prove to be a complex and difficult procedure because of HIV's genetic variability. There appear to be many different strains of HIV. What is more, the genetic structure of HIV appears to mutate over time within the same individual which poses further problems for vaccine development. Nevertheless, it has been possible to identify parts of the virus which remain relatively constant across strains, and whilst vaccine trials involving humans are unlikely for some time, there is some hope that in time a vaccine can be developed.

More recently it has been suggested that with some assistance an individual's immune system may be able to fight HIV. Researchers at the University of California, San Francisco announced at the end of 1986 that they had identified a small sub-set of T-suppressor cells which were able to halt viral replication under laboratory conditions. If the replication of such cells could be stimulated in some way then it could be possible for the body to mount its own defence against HIV. Other researchers are currently investigating the possibility that a different type of T-cell, the killer T-cell, might be stimulated so as to recognise and attack HIV.

But therapies such as these are very much in the early stages of their development. Assuming that some of them prove to be successful, it is unlikely that they could be widely available before the early 1990s.

Holistic therapy

In the absence of effective drug therapy against HIV infection, attention has been focused on the sorts of holistic intervention that are possible. There have been a number of reports suggesting that people with HIV infection and/or AIDS can gain a great deal from holistic therapies. These treatments range in their sophistication from those which attempt to ensure that the person gives careful attention to diet, exercise and sleep to those which advocate intervention by specialist practitioners in macrobiotics, homeopathy and acupuncture. Guided imagery and relaxation exercises have also been used to reduce the levels of stress experienced by people with HIV infection and/or AIDS. Tatchell's (1986)

recent self-help guide to intervention of this type summarises many of the options available, and the September 1986 edition of the natural health journal *EastWest* contains a number of articles detailing the claimed success of therapies such as these in the United States.

References

Tatchell, P. (1986) *AIDS – A Guide to Survival*, London, Gay Men's Press.

4 STRATEGIES AND MATERIALS

This section looks at the health education strategies and materials we have developed and piloted with over 200 participants on **Learning about AIDS** courses and they are designed to complement existing forms of provision. They are not to be used prescriptively, but as part of a participatory learning programme about AIDS.

HOW TO USE THE MATERIALS

These materials consist of a variety of exercises which can be used selectively in courses of varying lengths. There are introductory and final exercises, together with several intermediary exercises which should be used selectively (depending on the professional background of the participants).

The exercises are as follows:

Exercise 1 – Expectations of the Learning about AIDS course (for use with all groups)
Exercise 2 – Beliefs about AIDS (for use with all groups)
Exercise 3 – Advice to others (case studies)
Exercise 4 – Advice to others (prevention)
Exercise 5 – Guidelines for staff
Exercise 6 – Confidentiality

} **Select from these depending on group and time available**

Exercise 7 – Personal agenda setting (for use with all groups)
Exercise 8 – Professional agenda setting (for use with all groups)

The recommended *minimum* length of time for a **Learning about AIDS** course is two half days and the *maximum* length for a course using these particular materials is three full days. Figure 8 provides an overview of what a **Learning about AIDS** course of minimum length might look like. The times allocated to each task will inevitably vary depending on the group, their previous experience and interest and what they identify as areas of concern (see Exercise 1 in which participants identify their expectations of the course). Day 2 should ideally follow several weeks after Day 1, by which time participants will have undertaken specified tasks (eg reading District/Local guidelines).

FIGURE 8 Suggested outline of minimum Learning about AIDS course (two half days)

DAY 1	(both 3 hours in total)
05 mins	INTRODUCTIONS
20 mins	EXERCISE 1 Expectations
10 mins	GROUP FEEDBACK
20 mins	EXERCISE 2 Beliefs about AIDS
40 mins	TUTOR FEEDBACK
10 mins	Break
25 mins	EXERCISE 3 Advice to others
20 mins	GROUP FEEDBACK
20 mins	SUMMING UP WHAT WAS LEARNED AND IDENTIFYING OUTSTANDING AREAS
10 mins	DISTRIBUTION OF MATERIALS (guidelines, notes on confidentiality, local resources etc)

DAY 2	
10 mins	RECAP
40 mins	EXERCISE 5 Guidelines
15 mins	GROUP FEEDBACK
20 mins	EXERCISE 6 Confidentiality
10 mins	Break
20 mins	TUTOR FEEDBACK
20 mins	EXERCISE 7 or 8 Agenda setting
15 mins	EVALUATION OF LEARNING ABOUT AIDS COURSE

Longer courses will be able to devote more time to each of the exercises and to include the full range of materials.

WHAT THE MATERIALS DO NOT INCLUDE

Due to the immediate demand for materials it has not been possible to pilot materials relating to lay perceptions of health and illness, and those concerned with sexuality awareness. These materials will be included in the full **Learning about AIDS** pack which will be available early in 1988.

If health educators wish to familiarise themselves with materials available on sexuality, we suggest they look at the following: *Taught not caught* (Clarity Collective, 1985), *Demystifying homosexuality* (Human Rights Foundation Inc, 1984) and *The Mirror Within* (Dickson, 1985).

WHAT YOU WILL NEED

The health educator using these materials will need to bear several things in mind when planning **Learning about AIDS** courses.

- △ **Their own knowledge of HIV infection/AIDS needs to be correct and up-to-date**
- △ **An awareness of the likely level of knowledge of the professional group participating in the course**
- △ **The number of participants on the course; we recommend a maximum of twenty people with two health educators, and twelve participants with only one health educator**
- △ **The length of time needed for the course, bearing in mind the participants' needs and knowledge**
- △ **The setting for the course should be one which is conducive to participatory forms of learning. It should be comfortable with chairs arranged in a circle or semi-circle, rather than in rows**
- △ **An overhead projector or flip chart will be needed for the feedback sessions**
- △ **Domestic arrangements – it helps if tea and coffee can be made available in the work room, so that sessions can follow on from one another with minimum disruption**
- △ **Participants will need writing materials for the exercises**

△ **Copies of:**
District Health Authority guidelines on Infection Control
District Health Authority policies on HIV infection and AIDS
Local Authority policy statements in relation to Education, Environmental Health and Social Services
Professional Association and Trade Union documents on HIV infection and AIDS, particularly in relation to confidentiality
Literature from voluntary organisations, such as the Terrence Higgins Trust

△ **Local addresses of:**
Counselling services
Lesbian and Gay switchboard
Friend (Gay and Lesbian counselling group)
Special clinics and Departments of Genito-Urinary medicine
Family Planning clinics
Support groups for those who are antibody positive, and/or people with AIDS
Support/counselling services for IV drug users
Blood Transfusion centres

△ **Leaflets and posters for display.**

INTRODUCTIONS (for all participants)

Spend about 5 minutes introducing yourself to the group – your name, where you work, and how you can be contacted. Explain any domestic arrangements.

Ask the group to introduce themselves to each other. Depending on the time available this may take different forms. If you only have a half day available, it should be sufficient at this stage if participants give their names and where they work. If you are starting a 3 day course, then you will have more time for general introductions and may want to use warm-up exercises (such as those detailed in *Drinking Choices* (TACADE, 1983) or *Working with Groups* (HEC, 1983)).

EXERCISE 1 – EXPECTATIONS

FOR ALL PARTICIPANTS

Aims – This exercise is designed to help health educators gain a clear idea of the participants' expectations of the course. It serves to set an agenda, and information from this exercise will also be useful at the end of the course to determine whether group expectations have been met.

If at the end of the course there are areas that you haven't covered sufficiently you may want to discuss with the participants the need for follow up work.

How to run the exercise

For this you will need the appropriate number of copies of *Exercise Sheet 1a* and *1b*. *Exercise Sheet 1a* should be distributed to all participants and the instructions read out so that everyone is clear what they have to do, that is to write down their expectations of what they would like to happen in the **Learning about AIDS** course. It will probably take participants about 5 minutes to do this.

Then ask participants to arrange themselves into small groups of five or six people and discuss their expectations as a group for about 15 minutes. One person in each group will be nominated to report back and will make notes (on *Exercise Sheet 1b*) of the common themes which emerge during the discussion.

When each of the groups have finished the task ask them to come back as a large group and listen to the report back from each group. The health educator(s) will write down the main points on an overhead projector transparency (OHT) or flip chart without entering into a discussion on any of the topics.

What the exercise is likely to elicit

The themes which emerge from this exercise tend to vary depending on the professional background of the group and their previous knowledge of HIV infection and AIDS.

Here are some of the themes which have emerged in our pilot work using this exercise:

FACTS/INFORMATION about the disease –

- where it originated from;
- how it is transmitted;
- which groups of people are most likely to be affected;
- effectiveness of screening programmes;
- the numbers of people currently infected and future projections on a local, national and worldwide scale;
- life expectancy of people with AIDS (PWA) once AIDS is diagnosed;
- current treatment for PWA;
- current medical research, particularly in relation to developing a cure.

INFORMATION about public responses to the disease –

- the government response to the disease and the effectiveness of this;
- local health/education/social services responses to the disease and the action they have taken.

PERSONAL CONCERNS –

- how to prevent oneself from coming into contact with the disease;
- personal fears about meeting someone with the disease;
- how to overcome own prejudice towards gay men;
- how to explain the disease to children;
- personal anxieties about the effect of the disease on own sexuality – should I stay celibate?

PROFESSIONAL CONCERNS –

- how to care for PWA in the community/hospital;
- the correct nursing approach to PWA;
- the psychological effects of having AIDS;
- how to discuss the disease in schools (particularly Roman Catholic and other religious schools);
- how to introduce sex education into schools; what is appropriate for different age groups?
- how to answer questions honestly and accurately;
- how to answer 'what if . . .' questions;
- which health education method is the most appropriate;
- what advice to give to young people about to enter a sexual relationship;
- issues to do with confidentiality.

PLANNING responses to HIV and AIDS –

- how to go about this, who to involve, what has been done elsewhere.

RESOURCES available –

- information on self-help groups, voluntary organisations, counselling services, Department of Genito-Urinary Medicine/Special or STD clinics;
- leaflets, books, videos.

EXPLORATION OF GROUP'S FEELINGS towards the disease –

- in relation to sexuality – to be able to feel at ease in discussions of this nature;
- in relation to the media response.

Given the wide ranging expectations identified above, it is important that the health educator(s) feel confident to address each of these issues, or at least knows where to direct the participants for further information/resources.

In those instances where the list of expectations far exceeds what can be realistically achieved within the time allocated for the **Learning about AIDS** course, it may be necessary to ask the participants to decide collectively which priority areas they would like to concentrate on. This can be done by asking them to return to their small groups and selecting one priority area. Each group then feeds back their chosen topic and the sum of these is regarded as the group's priority expectations for the duration of the course.

By the end of the exercise

- you should have displayed in a prominent position the group's expectations of the course.

EXERCISE 1a

EXPECTATIONS

Using this sheet of paper write down what you would like to happen in this **Learning about AIDS** course.

What I would like to happen

EXERCISE 1b

SMALL GROUP EXPECTATIONS

Using this sheet of paper write down the common expectations which emerged from your group discussion.

What we as a group would like to happen

EXERCISE 2 – BELIEFS

FOR ALL PARTICIPANTS

Aims – this exercise is designed to elicit the current beliefs participants hold about HIV infection and AIDS. After this the health educator(s) will be able to confirm, clarify and question current knowledge held by the participants.

In situations where you are working with a group which has a limited understanding of AIDS you will need to devote *more* time to this exercise (in some instances we have taken up to two hours with this exercise).

How to run the exercise

For this you will need the appropriate number of copies of *Exercise Sheet 2a* and *2b*. *Exercise Sheet 2a* should be distributed to *all* the participants and the instructions read out so that everyone is clear what they have to do, that is to write down three things they have heard about AIDS (from whatever source and irrespective of whether they personally believe it to be true). The participants are then asked to tick whether they believe each of the statements to be TRUE, FALSE, or NOT SURE ABOUT. It will probably take participants about 5 minutes to do this.

Then ask them to arrange themselves into different small groups of five or six people and to discuss as a group each of the statements they have written down. One person in each group will be nominated to report back and will make notes (using *Exercise Sheet 2b*) of the areas of agreement, disagreement, and uncertainty for each of the statements. This process will take about 15 minutes (though it may take longer if there is disagreement amongst the group, or if there are many areas of uncertainty).

When each of the groups has finished the task ask them to re-form as a large group. Taking each group in turn listen to the areas of agreement, disagreement and uncertainty and confirm, clarify or question each of the statements that are made. This tutor feedback session will take approximately 40 minutes, but its length will vary depending on the participants' level of knowledge.

What the exercise is likely to elicit

The beliefs which emerge from this exercise tend to vary considerably depending on the professional background of the group and their previous knowledge of HIV infection and AIDS.

Here are some of the beliefs which have emerged during our training sessions and examples of our responses:

AREAS OF AGREEMENT –

"AIDS is spread by promiscuous homosexual men"

The participants believed this statement to be TRUE. The health educator needs to explain that it is *neither* promiscuity *nor* gay men which spreads AIDS. AIDS is spread by the exchange of body fluids (Section 3.4) and in the case of sexual activity it is not the number of partners, but the form of sexual act that matters. Non-penetrative intercourse in which there is no exchange of body fluids does not put people at risk of AIDS, no matter how many partners they have.

"AIDS is spread through blood transfusions"

The participants correctly believed that the virus can be spread through blood. The role of the health educator here is to put the risk in perspective, to refer to the number of cases of AIDS where blood transfusions were seen to be implicated and to explain the current procedures for screening blood (Section 3.4).

"The more partners you have the more at risk you are"

The participants believed this statement to be TRUE. Again the health educator needs to clarify the point that it is not necessarily the number of partners a person has, but what they do with them and whether or not they practice 'safer sex' (ie with no exchange of body fluids, using condoms, or mutual masturbation).

AREAS OF DISAGREEMENT –

"AIDS can be spread by living with someone who has it"

There was disagreement over this statement. The statement is FALSE. AIDS cannot be transmitted socially (Section 3.4).

"Everyone is at risk of AIDS"

There was disagreement over this statement. People are only at risk of AIDS if they put themselves in risky situations, ie do not practice 'safer sex', exchange dirty needles (if IV drug users), do not cover open wounds (Section 3.6).

"AIDS can be transmitted by women to women"

There was disagreement over this statement. In theory if a woman is HIV positive and exchanges body fluids (eg vaginal and cervical secretions) with another woman, then the virus could be transmitted.

"There are 'innocent' and 'guilty' victims of AIDS"

There was disagreement over this statement. Some participants felt that haemophiliacs and babies were 'innocent' victims of the disease, whilst gay men, prostitutes and IV drug users were 'guilty' victims of the disease. This distinction is not helpful to anyone, and it can be positively damaging if people caring for PWA hold these beliefs as they may interfere with the care they give (Section 3.3).

AREAS OF UNCERTAINTY –

"AIDS originated in Africa"

We do not yet know where the AIDS virus originated. There are various speculations about this (Section 3.2). Nor do we know where the common cold or the Herpes virus originated. Whilst it may be helpful to have this information, we currently live with considerable uncertainty and we need to accept this. What we do know in relation to the AIDS virus is how it is transmitted and we can act on this information to prevent it spreading.

"AIDS is spread through kissing"

Whilst the virus has been isolated from saliva within the laboratory setting, there have been no known cases of the virus being transmitted through saliva. There are also substances present in saliva which inactivate the virus (Section 3.4).

By the end of the exercise

- ▲ you will have discussed each of the statements and confirmed, clarified or questioned their accuracy.

Do not be afraid to admit that you are unsure of the evidence. It is better to refer participants to another source, or to say that you will find out what the evidence is by the time of the next session than to make things up or give a false sense of certainty.

EXERCISE 2a

BELIEFS ABOUT AIDS

Using this sheet of paper, list three things you have heard about AIDS. In the column on the right, tick whether you believe the statement is TRUE, FALSE or you are NOT SURE about it.

	TRUE	FALSE	NOT SURE
1.			
2.			
3.			

EXERCISE 2b

BELIEFS ABOUT AIDS

When you have listed your three statements, divide into small groups and discuss them.

Use this sheet of paper to list areas of AGREEMENT, DISAGREEMENT and UNCERTAINTY.

AGREEMENT

DISAGREEMENT

UNCERTAINTY

EXERCISE 3 – ADVICE TO OTHERS

FOR USE SELECTIVELY

Aims – these case studies are designed to help participants disentangle what they 'know' about HIV infection and AIDS from what they 'feel'. The aim of the exercise is to elicit reactions to certain situations and for the participants to consider how their response may be tempered by personal feelings, rather than based on knowledge of the disease.

How to run the exercise

This exercise consists of seven case studies which are appropriate to health educators in a variety of professional settings (Exercise Sheets a–d are case studies which can be used by any group, e and f are specifically for teachers and g is directed at parents). Before the exercise you will need to have selected and copied the case studies which are most relevant to your particular group and to have thought about the issues which are likely to be raised by the case studies.

Distribute a copy of the selected case studies to the participants as appropriate. Ask them to write down their reactions to the case study and the advice they would give. It will probably take participants about 5 minutes to do this.

Divide the participants into small groups of four or five based on the case study they looked at. Ask them as a group to discuss their responses for 15 to 20 minutes. One person in each group will be nominated to report back and will make notes of the issues which emerge during the discussion.

When each of the groups has finished the task ask them to re-form as a large group and listen to the report back from each group. This should take about 30 minutes depending on how much clarification is needed from the health educator.

What the exercise is likely to elicit

Each of the case studies is likely to elicit participants' personal fears and reactions to the following:

- starting a new sexual relationship
- being in a relationship with someone who is about to nurse PWA
- being kissed by someone who is HIV antibody positive
- working with someone who may be at risk
- childrens' fears of AIDS
- giving mouth-to-mouth resuscitation to a potentially at-risk person
- children learning about condoms through the media.

The action that participants say they would take in each of the scenarios may be based on personal fears rather than their knowledge of HIV infection and AIDS. Their actions may also be based on the level of knowledge they feel that it is appropriate to give others, for example schoolchildren, as well as their willingness to tackle their own homophobia and that of friends and colleagues.

By the end of the exercise

You will have,

- discussed each of the selected case studies and had the opportunity to reiterate information about the precise modes of transmission and at-risk behaviour
- introduced the subject of 'safer' sex (if this has not already been discussed in Exercise 2)
- explored people's fears and anxieties in relation to HIV infection and AIDS.

EXERCISE 3a

ADVICE TO OTHERS (CASE STUDY)

GENERAL

A woman you know has a new boyfriend, and they want to start a sexual relationship. She comes to you for advice because she is afraid of catching AIDS, but doesn't want to be celibate for the rest of her life.

What is your reaction?	What do you do?

EXERCISE 3b

ADVICE TO OTHERS (CASE STUDY)

GENERAL

Your girlfriend who is a nurse has recently been given the chance of working on a ward where people with AIDS are occasionally nursed. For her this means promotion.

What is your reaction?	What do you do?

EXERCISE 3c

ADVICE TO OTHERS (CASE STUDY)

GENERAL

A friend you haven't seen for a long time comes to see you and greets you with a kiss on the mouth. A few weeks later when you next meet he confides in you that he is antibody positive.

What is your reaction?	What do you do?

EXERCISE 3d

ADVICE TO OTHERS (CASE STUDY)

GENERAL – WORKPLACE

A man you know at work has had the test for antibodies to HIV, and the test result is negative. Some people at work have found out that he has had the test and have advised you to avoid him.

What is your reaction?	What do you do?

Exercise 3e

ADVICE TO OTHERS (CASE STUDY)

TEACHERS – PRIMARY SCHOOL

One of the girls in your fourth year junior class is consistently absent from games lessons. You notice her reluctance to join in the usual playground activities with friends. From talking with her you discover that she is acutely afraid of catching AIDS, as a result of the warnings she has received from her father.

What is your reaction?	What do you do?

EXERCISE 3f

ADVICE TO OTHERS (CASE STUDY)

TEACHERS – SECONDARY SCHOOL

A dispute between two fifth form boys leads to a fight in the playground at lunch-time in which one is badly winded and needs artificial respiration. As a teacher you have been trained in First Aid. The boy in question is known to you as a habitual user of injected drugs. A colleague refuses to give mouth to mouth resuscitation.

What is your reaction?	What do you do?

EXERCISE 3g

ADVICE TO OTHERS (CASE STUDY)

PARENTS

Your neighbour comes to you in a state of agitation. Their nine year old son has seen a recent Department of Health TV commercial on AIDS and subsequently asked them what a condom is. Your neighbour is disgusted that a child of this age should have heard such a word.

What is your reaction?	What do you do?

EXERCISE 4 – ADVICE TO OTHERS (PREVENTION) *FOR USE SELECTIVELY*

Aims – this exercise is designed to ascertain the nature of the knowledge that participants have acquired during the course. The aim of the exercise is for participants to translate recently acquired knowledge into practical advice for others.

This exercise may be used instead of *Exercise 3* when time is limited.

How to run the exercise

For this you will need the appropriate number of copies of *Exercise Sheet 4*. These should be distributed to all participants who should then be asked to list the advice they would give to others (either in their professional capacity or as colleagues, friends or parents) to prevent them from becoming infected by HIV. This should take about 8 minutes.

Then ask them to arrange themselves into small groups of five or six people and to discuss as a group for about 20 minutes the advice they have written down. They will be asked to question whether this advice is appropriate and how they might attempt to give this advice. One person in each group will be nominated to report back and will make notes of the issues that emerge.

When each of the groups has finished the task ask them to re-form as a large group and listen to the report back from each group in turn. Write down the main points on an overhead transparency (OHT) or flip chart. The health educator will need to be prepared to give guidance on some of the issues raised in this exercise. This part of the exercise will take about 20 minutes depending on the knowledge of the group and their confidence in advising others.

What the exercise is likely to elicit

The areas of advice which emerge from this exercise tend to vary depending on the professional background of the group and their own roles as health educators.

Here are some of the themes which have emerged through using this exercise (the items with * indicate further discussion – see below):

PERSONAL HYGIENE

- ▲ cover cuts
- ▲ acupuncture, tatooing and ear-piercing – check that equipment is sterilised between use
- ▲ don't share needles, razors or sex toys
- ▲ don't engage in blood rituals (eg blood brothers/sisters)
- ▲ clean up blood spillage with 1:10 dilution of household bleach.

SEXUAL RELATIONSHIPS

- ▲ *encourage a committed relationship with a single trusted partner
- ▲ *postpone 'full' sexual relationships until more information is known about the partner
- ▲ *use a condom every time you have vaginal, anal, or oral intercourse
- ▲ *use a spermicide containing Nonoxynol 9.

EDUCATION

- ▲ there should be more positive education in schools about AIDS and sexuality.

Some of these items of advice raise yet further questions which the health educator will need to be prepared to respond to:

- ▲ the fear of losing a partner if monogamy is insisted on
- ▲ what about religious aspects to using condoms?
- ▲ what about using a condom if the partner has been sterilised?
- ▲ what if the person wishes to become pregnant?

- what about the taste of condoms in oral sex?
- how can condoms be made more attractive?
- how can we give advice on the proper use of condoms?
- how to learn about forms of sexual expression which do not involve penetrative intercourse.

By the end of the exercise

You will have,

- a clear idea of how much has been learned on the course so far;
- the ability of participants to make sense of their knowledge and apply it to practical situations will also be apparent.

The items raised during this exercise can be placed in a prominent position and added to during the remainder of the course.

EXERCISE 4

ADVICE TO OTHERS – PREVENTION

Using this sheet of paper and your knowledge about AIDS, list:

What advice you would give to **others** to prevent them from being infected by HIV (Human Immunodeficiency Virus).

EXERCISE 5 – GUIDELINES FOR STAFF

FOR USE SELECTIVELY

Aims – to familiarise participants with their Health, Local or Education Authority guidelines on HIV infection and AIDS. To clarify information contained in the guidelines and to identify areas not covered by the guidelines.

How to run the exercise

For this exercise you will need a copy of the relevant Authority guidelines for each of the participants. On a two or three day course it is ideal if these can be distributed at the end of Day 1 or 2 so that participants can have the opportunity to read them overnight. This is a good exercise to begin the day with.

Distribute a copy of *Exercise Sheet 5* to each of the participants and ask them to complete it making reference to the appropriate guidelines. You will need to allow at least 15 minutes for this and in cases where participants have not had the time to read the guidelines before, you will need longer.

When each of the participants has completed *Exercise Sheet 5* ask them to arrange themselves into small groups and discuss their responses. It is possible to use this exercise with mixed professional groups, in which case they each have a copy of the relevant guidelines and divide into small groups based on their professional background. Again, one person will be nominated to report back and will make notes of the issues which emerge from each of the three questions on *Exercise Sheet 5*.

When each of the groups has finished the task ask them to re-form as a large group and listen to the report back from each group in turn. This discussion will take at least 30 minutes and it is important to record the points that are raised so they can be fed back to those responsible for drawing up and amending the guidelines. The health educator may wish to invite someone who has been involved in drawing up the guidelines to answer queries and to receive feedback on the appropriateness of the advice which they contain.

What the exercise is likely to elicit

The points raised will vary according to the professional background of the participants and the comprehensiveness of the guidelines.

Here are some of the points this exercise has elicited:

INFORMATION IN THE GUIDELINES WHICH PARTICIPANTS DIDN'T KNOW BEFORE

- the length of the 'high risk' group list
- men in prison = 'high risk'
- innoculation risks vs high risk
- the possible dangers of attempting to disconnect a needle from a hypodermic syringe after use.

AREAS OF UNCERTAINTY

- mechanism for transporting blood from 'high risk' people to the laboratory
- whether or not gloves should be used to take blood from every patient

AREAS WHICH NEED TO BE INCLUDED

- information on counselling provision available
- guidance on confidentiality
- where to obtain supplies of waterproof plasters
- facilities for disinfection.

By the end of the exercise

- there will be three lists of information relating to each of the questions discussed. This information can be passed on to the relevant Authority officer so it can be taken into account when revised guidelines are prepared.

EXERCISE 5

GUIDELINES FOR STAFF

After having read your District Health Authority, Local or Education Authority guidelines on HIV infection and AIDS, use this sheet of paper to answer the following questions:

1 What was there in the guidelines which you didn't know before?

2 What was there in the guidelines which you are unclear about?

3 What areas can you identify which are not in the guidelines, which you feel ought to be covered?

EXERCISE 6 – CONFIDENTIALITY

FOR USE SELECTIVELY

Aims – this exercise is designed to remind different client groups about the rules of confidentiality to be observed in their work. The exercise also aims to look at the adequacy of these rules in the light of HIV infection and AIDS.

How to run the exercise

For this exercise you will need sufficient copies of the relevant employing authority regulations on confidentiality to distribute to each of the participants. You will also need for yourself a copy of the relevant professional Codes of Conduct in relation to confidentiality (for example, those produced by the BMA, RCN).

When running the course with participants who are not required themselves to observe a professional Code of Conduct, it is useful to discuss with them the rules of confidentiality relating to their colleagues.

On a two or three day course it helps if participants are given time to remind themselves of their Authority's regulations on confidentiality. This can be done by distributing copies of these at the end of Day 1 or 2 so that participants have the opportunity to re-read them overnight.

Distribute a copy of *Exercise Sheet 6* to each of the participants and ask them to complete it with reference to the rules of confidentiality they currently observe. This will take about 7 minutes to complete.

When each of the participants has completed *Exercise Sheet 6* ask them to arrange themselves into small groups and discuss their responses. Where you have more than one professional group on a **Learning about AIDS** course, divide the participants into groups based on their professional background. One person from each group will be asked to report back and will make notes of the points which emerge. This discussion will take about 20 minutes depending on the professional background of the participants.

When each of the groups has finished the task ask them to re-form as a large group and listen to the report back from each group in turn. Write down the main points on an overhead transparency (OHT) or flip chart. The health educator will need to give guidance on the points raised and may need to make reference to the appropriate professional Code of Conduct.

What the exercise is likely to elicit

The points raised will vary depending on the professional background of the participants and the appropriateness of the current rules of confidentiality to HIV infection and AIDS.

As issues to do with confidentiality can be emotive, there may be tension between and within groups on this subject. This may be more marked when using the exercise with mixed professional groups who are critical of each others' Codes of Conduct.

Here are some points raised through using this exercise:

RULES OF CONFIDENTIALITY CURRENTLY OBSERVED

- ▲ checking the authenticity of phone calls about clients
- ▲ ensuring privacy for discussions with clients
- ▲ obscuring names from case notes (so other staff cannot see)
- ▲ not discussing client details with other staff, on or off duty
- ▲ information about client not given to others without clients consent

ADEQUACY OF CURRENT RULES

- ▲ problem ensuring that records are safe
- ▲ problem with typing letters about clients
- ▲ problem of what to write on clients' records.

By the end of the exercise

- ▲ you will have identified those areas of confidentiality currently observed together with areas which may need revising in the light of HIV infection and AIDS.

EXERCISE 6

CONFIDENTIALITY

Using this sheet of paper please provide information on the following:

1 **In terms of your work, what rules of confidentiality do you observe?**

2 **To what extent do you feel these rules of confidentiality are adequate in relation to HIV infection and AIDS?**

EXERCISE 7 – PERSONAL AGENDA SETTING

FOR ALL PARTICIPANTS

Aims – This exercise is one of the two final exercises and is designed to help participants identify aspects of AIDS education they are personally concerned with which were not fully covered in the course.

Exercise 7 may be used in conjunction with *Exercise 8*, or independently, depending on the time available.

How to run the exercise

You will need the appropriate number of copies of *Exercise Sheet 7*. These should be distributed to all participants. Ask them to reflect on the **Learning about AIDS** course:

- what were their expectations at the outset?
- have these expectations been met?
- what have they learned on the course?
- what aspects of HIV infection and AIDS do they need to find out more about?

Then ask the participants to list anything they need to find out for themselves in relation to AIDS, and to identify where they propose to obtain this information from. This should take about 10 minutes.

When the participants have completed their list, ask them to consider how long it will take them to find out about all the items on their list. (Two to three weeks after the end of the course is usually long enough).

What the exercise is likely to elicit

▲ more information on current research	LOOK in medical journals and books
▲ queries about the safety of going to the dentist	ASK the dentist
▲ personal queries about safer sex	DISCUSS with partner

There is no group feedback for this exercise. The information constitutes a personal agenda and is for the participants to take away with them.

By the end of the exercise

- each participant will have a personal agenda of items they wish to find out more about.

EXERCISE 7

PERSONAL AGENDA SETTING

Using this sheet of paper, make a list of the things you need to find out more about in connection with AIDS. Try and identify where you will go to find out about these things.

Things I still need to find out about	Where I will go to find out about them

EXERCISE 8 – PROFESSIONAL AGENDA SETTING *FOR ALL PARTICIPANTS*

Aims – This exercise is one of the two final exercises and is designed to help participants identify aspects of AIDS education they are professionally concerned with which were not fully covered in the course.

Exercise 8 may be used in conjunction with *Exercise 7*, or independently, depending on the time available.

How to run the exercise

You will need the appropriate number of copies of *Exercise Sheet 8*. These should be distributed to all participants. Ask them to reflect on the **Learning about AIDS** course:

- ▲ what were their expectations at the outset?
- ▲ have these expectations been met?
- ▲ what have they learned on the course?
- ▲ what aspects of HIV infection and AIDS do they need to find out more about?

Then ask the participants to list any things they need to find out for themselves in relation to AIDS, and to identify where they propose to obtain this information from. This should take about 10 minutes.

When the participants have completed their list, ask them to consider how long it will take them to find out about all the items on their list. (Two to three weeks after the end of the course is usually long enough). Then suggest that participants enter into a 'contract' with a colleague and arrange to meet them in a few weeks' time to discuss the success they have had in obtaining further information.

What the exercise is likely to elicit

▲ how much information to give children without causing panic?	ASK Local Education Authority adviser
▲ what is likelihood of meeting a child who is HIV antibody positive?	LOOK in medical journals and books, Government information services
▲ how can higher standards of hygiene be promoted amongst colleagues?	DISCUSS with colleagues
▲ what is the Local Authority policy on HIV infection and AIDS?	ASK relevant administrator
▲ who is in charge of First Aid in the workplace?	ASK Health & Safety Officer

There is no group feedback for this exercise. The information constitutes a professional agenda and is for the participants to take away with them. It is hoped that participants will be able to obtain the information they require by the date they have set.

By the end of the exercise

- ▲ each participant will have a professional agenda of items they wish to find out more about;
- ▲ each participant will have entered into a contract with another person to discuss their success in this activity.

EXERCISE 8

PROFESSIONAL AGENDA SETTING

Using this sheet of paper, make a list of the things you need to find out about AIDS in connection with your work. Try and identify where you will go to find out about these things.

Things I still need to find out about	Where I will go to find out about them

Concluding a Learning about AIDS course

At the end of each day of a **Learning about AIDS** course we suggest you spend at least 15 to 20 minutes gaining feedback from the participants about what has happened that day.

When you come to the end of the course go back to the list of expectations generated by *Exercise 1*. Discuss each of these expectations in turn and ask the participants which areas are outstanding and need further attention. Make a note of these and take them into account when planning future courses. (Further guidelines for evaluating and developing participatory approaches to AIDS education are contained in the next section, pages 67–69).

Finally, thank the participants and your colleague(s) for their contributions and remind everyone where they can contact you should they need to do so.

References

Clarity Collective (1985) *Taught not Caught. Strategies for Sex Education*, New York, Learning Development Aids.

Dickson, A. (1985) *The Mirror Within: A New Look at Sexuality*, London, Quartet Books.

Evans, M. & Satow, A. (1983) *Working with Groups*, London, Health Education Council.

HEC/TACADE (1983) *Drinking Choices*, London, Health Education Council/TACADE.

Human Rights Foundation Inc. (1984) *Demystifying Homosexuality: A Teaching Guide about Lesbians and Gay Men*, New York, Irvington.

5 GUIDELINES FOR EVALUATING AND DEVELOPING PARTICIPATORY APPROACHES TO AIDS EDUCATION

These materials have been developed using a participatory approach to AIDS education. They are not prescriptive and should not be used in such a way. The evaluation of the **Learning about AIDS** courses should therefore be a formative process which is continuously evolving and responding to participants' needs. The mechanism by which this is done has to be consciously and deliberately built into the way **Learning about AIDS** materials are used. Please remember that these are interim materials and will need further developing in the light of the findings of the continuing **Learning about AIDS** project, the feedback we receive from users (ie yourself), as well as changes in knowledge about HIV infection and AIDS.

When evaluating **Learning about AIDS** courses you will need to pay attention to both the process of the course and the outcome.

PROCESS EVALUATION

You can evaluate the *process* by asking a series of questions at the end of the course. These questions should be directed at three groups of people: 1) yourself; 2) the colleague(s) working with you; and 3) the course participants. Examples of the sorts of questions you can use to elicit feedback at the end of each course are as follows:

SELF

- △ **Was the course genuinely participatory?**
- △ **Did all the participants contribute?**
- △ **What was the balance between the contributions you gave and those given by the participants?**
- △ **Which Exercises worked well?**
- △ **Which Exercises worked less well?**
- △ **Did you allow enough time for each Exercise?**
- △ **Was there any factual information which needs further clarification?**

COLLEAGUES

It is often easier to judge how a course went when you are working with another person. Before the course you will need to divide up responsibilities and you can take it in turns to observe the group whilst the other person is organising group activities.

At the end of the course it is useful to ask the same questions of your colleague(s) as you do of yourself and give constructive feedback. Discuss what changes you would want to make in the future and make a note of these.

COURSE PARTICIPANTS

At the end of each course you need to allow sufficient time for feedback. The following questions provide you with a starting point, but you may want to ask more:

- △ **Did participants feel they had enough opportunity to contribute?**
- △ **Did participants feel their contributions were received non-judgementally?**
- △ **Did participants feel their questions were answered satisfactorily?**
- △ **Did participants feel they were reassured by the course?**
- △ **What areas are still outstanding and need further attention?**
- △ **Is there a need to follow-up any of the above points with a further Learning about AIDS course?**

You will need to make a note of these responses and incorporate changes as necessary into future planning.

REVIEW

The responses elicited from yourself, your colleague(s) and the participants may not match; you may all have different perceptions of the course. It is important to identify these differences and to monitor the feedback you receive from a wide range of professional groups and when working with different colleagues. It may be that different professional groups have divergent expectations of the course, of a participatory approach and of the subject matter itself. You may observe common themes emerging after several courses and you can note these down and make changes accordingly.

OUTCOME EVALUATION

The outcome you are evaluating can be related to each of the models of health education we outlined earlier (see pages 9–10). Evaluating *information-giving* which aims to increase knowledge and change behaviour can be done in various different ways. In many instances, questionnaires are distributed before and after a course to judge changes in the level of knowledge achieved by the course. In relation to **Learning about AIDS** this is not an appropriate method. A participatory approach to AIDS education begins with what people already know about AIDS and builds on this. Devising a questionnaire to elicit levels of knowledge would inevitably involve making certain assumptions about the participants' knowledge without having met them. Additionally, an increased awareness and changes in the level of knowledge, do *not* necessarily lead to changes in behaviour (see also Gatherer, 1979). In many instances we have found a disjuncture between what people *know* about HIV infection and AIDS, what they *feel* and how they *act*.

It is more likely that change will come about if people feel more self-confident. Therefore a *self-empowering* approach in which participants can explore their fears and anxieties and work through these is likely to have longer term success. ***Exercise 3*** attempts to ascertain how people will react in given situations, but there is no direct evidence to believe that they will do what they say they will do. Their actions can best be evaluated by a follow-up course which includes a substantial amount of time devoted to identifying the extent to which participants' personal and professional agendas have been achieved (see ***Exercises 7*** and ***8***). If such a course is not possible, then you will need to devise other approaches to assess what people are currently doing and the progress they have made with their personal and professional agendas.

Another outcome of **Learning about AIDS** courses may be greater professional involvement in *community activities*. Our experience in running **Learning about AIDS** courses has indicated that participants often have a low level of awareness of the various voluntary groups concerned with HIV infection and AIDS. It is possible over time to evaluate the working relationships between professional and voluntary personnel. Again a follow-up session would provide the best opportunity for monitoring these developments.

Implementing policy changes in District Authority guidelines, and/or revising current Codes of Conduct in relation to confidentiality can be indications of the success of **Learning about AIDS** courses within the *social transformatory* paradigm. Health educators will

therefore need to monitor the progress of these initiatives and to evaluate the ease with which different professional groups achieve these goals. According to the social transformatory paradigm there are many other fronts on which changes need to take place (for example, changes in insurance policies, adequate resources for research into AIDS, caring for people with AIDS, monitoring media reports, and challenging homophobia generally). It is unrealistic to imagine that these changes will be achieved through **Learning about AIDS** courses on their own. But it is hoped that the process of participating in such courses will lead to a greater awareness of the social injustices surrounding AIDS and that participants may become involved more fully as the advocates of people with HIV infection and AIDS. Ultimately it should be remembered that the best judges of the effectiveness of a social transformatory approach will be those persons most affected in the current health crisis.

References

Gatherer, A. et al (1979) *Is health education Effective?*, Research Monograph No. 2, London, Health Education Council.

We are extremely keen to hear about your success in using and evaluating these preliminary **Learning about AIDS** materials. Please will you send your comments to:

Hilary Homans & Peter Aggleton
Faculty of Education and Community Studies
Bristol Polytechnic
Redland Hill
BRISTOL BS6 6UZ

6 RESOURCES FOR AIDS EDUCATION – 1

BOOKS

Participatory approaches to health education assume that health educators have a good understanding of the issues they intend to explore with client groups. If you feel unsure about issues to do with AIDS, then reading the following books is a good way to prepare yourself for the sorts of questions you may be asked. You can order them from any good bookshop.

The best introduction to many of the medical and social issues associated with AIDS is,

McKie, R. (1986) *Panic: the Story of AIDS*, London, Thorsons.

When you have read this, the following books will help consolidate your understanding of the relevant issues,

Altman, D. (1986) *AIDS and the New Puritanism*, London, Pluto Press.

Institute of Medicine, National Academy of Sciences (1986) *Mobilizing against AIDS*, London, Harvard University Press.

Patton, C. (1986) *Sex and Germs – the Politics of AIDS*, Boston, South End Press.

If you are likely to be concerned with the education of health care workers, you will probably find the following book of interest,

Miller, D. et al (1986) *The Management of AIDS patients*, Basingstoke, Macmillan.

OTHER PRINTED RESOURCES

Supplies of the Health Education Authority leaflet *AIDS: What Everybody Needs to Know* can be obtained free from,

Dept A
Box 100
Milton Keynes MK1 1TX

Copies of the booklet *Children at School and Problems Related to AIDS* produced for teachers by the Department of Education and Science can be obtained free from,

Publications Despatch Centre
Canons Park
Middlesex HA7 1AZ

Copies of the booklet *AIDS and Employment* produced by the Department of Employment and the Health & Safety Executive can be obtained free from,

The Mailing House
Leeland Road
London W13 9HL

A list of materials produced by the Terrence Higgins Trust is available from,

The Terrence Higgins Trust
BM AIDS
London WC1N 3XX

SOME USEFUL TELEPHONE NUMBERS

Department of Health Special AIDS line	0800 555777
Health Education Authority	01 631 0930
Welsh AIDS Campaign	0222 223443
Scottish AIDS Monitor	031 558 1167
Terrence Higgins Trust	01 833 2971
The Haemophilia Society	01 928 2020
Standing Conference on Drug Abuse	01 430 2341
AVERT	0403 864010

The London Lesbian and Gay Switchboard (01 837 7324) will answer general enquiries about AIDS 24 hours a day, and can put you in touch with groups such as SIGMA (an organisation for heterosexuals with a gay or bisexual partner), Body Positive (a support group for those diagnosed as having antibodies to HIV), London Gay Teenage Group, Young Lesbian Group, Gay Bereavement Project etc.

Help from the Samaritans is also likely to be available 24 hours a day.

The Healthline AIDS Information Service (01 980 4848) run by the College of Health has produced a number of pre-recorded tapes about AIDS which can be listened to over the telephone. Please be ready to give the number of the tape you want to listen to when you call.

136 What is AIDS?
229 Who's at Risk?
230 Testing & AIDS
232 Signs & Symptoms of AIDS
234 Safer Sex for Heterosexuals
225 Safer Sex for Gay Men & Bisexuals
236 Safer Sex for Haemophiliacs
237 Safer Sex for People who Inject Drugs
239 AIDS and Blood Transfusions
240 AIDS and Artificial Insemination
241 How to help someone with AIDS

FURTHER RESOURCES

A copy of the AIDS resource list produced by the Health Education Authority is enclosed with these preliminary **Learning about AIDS** materials. This identifies a wide range of health education materials relating to HIV infection and AIDS. Do remember though that most of the material referred to on this list has been produced within the context of an information-giving approach to education about AIDS. You will need to consider carefully how best to use this material within the context of the more participatory styles of AIDS education advocated here.

LEARNING ABOUT AIDS – UPDATE

Prepared by Hilary Homans & Peter Aggleton
Faculty of Education & Community Studies
Bristol Polytechnic

LEARNING about AIDS
INTERIM MATERIALS

Introduction

Since Learning about AIDS – Interim Materials were published in June 1987 there have been a number of important developments relating to HIV infection and AIDS. We have taken the opportunity of this update to provide health educators with information about some of these in order that Learning about AIDS – Interim Materials can be used more effectively. The full Learning about AIDS programme will be available as planned in 1988.

Definitions

In August, the Centers for Disease Control in Atlanta, USA published a revised case definition of AIDS. From September 1st, this new definition will also be used by the Communicable Diseases Surveillance Centre here in Britain. The most important change is the inclusion of a broader range of AIDS indicator diseases including HIV encephalopathy and HIV wasting syndrome. Details of this new definition can be found in Communicable Diseases Report 87/34 published by the Public Health Laboratory Services, Communicable Diseases Surveillance Centre, 61 Colindale Avenue, London NW9 5EQ.

Statistics

Table 1 below identifies the total reported cases of HIV infection in England, Wales and Northern Ireland up until the end of August 1987.

Cumulative totals of HIV antibody positive persons reported, by transmission characteristic, to week 87/34

Transmission characteristic	Male	Female	Unknown	Total
Homosexual/bisexual	3009	–	–	3009
Intravenous drug abuser (IVDA)	256	135	5	396
Homosexual & IVDA	38	–	–	38
Haemophiliac	975	4	–	979
Recipient of blood	32	20	–	52
Hetrosexual contact*				
contact of above groups	4	49	1	54
contact of other groups	92	58	–	150
no information	10	19	–	29
Child of HIV antibody positive parent	8	7	2	17
Several risks	8	–	–	8
No information	636	26	21	683
Totals	5068	318	29	5415

* Persons without other identified risks from countries where heterosexual transmission is believed to play an important role and who were previously allocated to "Other risks", have now been reclassified to heterosexual transmission.

Source: Communicable Diseases Reports. 87/34.

Table 2 identifies the total reported cases of AIDS in the UK as a whole at the end of August 1987

Cumulative totals of UK reports of AIDS cases (deaths) to 31 August 1987

Transmission characteristic	Male	Female	Total
Homosexual/bisexual	860 (476)	–	860 (476)
Intravenous drug abuser (IVDA)	10 (4)	3 (2)	13 (6)
Homosexual & IVDA	15 (8)	–	15 (8)
Haemophiliac	56 (41)	1 (-)	57 (41)
Recipient of blood: abroad	9 (6)	6 (3)	15 (9)
UK	6 (5)	2 (2)	8 (7)
Heterosexual:			
possibly infected abroad	17 (6)	7 (6)	24 (12)
UK (no evidence of being infected abroad)	3 (2)	5 (4)	8 (6)
Child of HIV antibody postive parent	4 (2)	7 (4)	11 (6)
Other	–	1 (1)	1 (1)
Undetermined	1 (-)	–	1 (-)
Totals	981 (550)	32 (22)	1013 (572)

Source: Communicable Diseases Report. 87/34.

Table 3 identifies the total reported cases of AIDS in the United States as of mid August 1987.

40,845 and counting ...
AIDS Cases as Reported by the CDC as of August 24th, 1987

Residence of Cases	Number of Cases		Residence of Cases	Number of Cases
New York State		11656	Missouri	275
New York City	10554		North Carolina	272
California		9419	Arizona	260
San Francisco	4009		Minnesota	221
Los Angeles	3506		Oregon	197
San Diego	525		Indiana	189
Florida		2754	Hawaii	162
Miami	1149		South Carolina	154
Ft Lauderdale	508		Alabama	148
Texas		2714	Oklahoma	146
Houston	1347		Wisconsin	138
Dallas	784		Tennessee	126
New Jersey		2352	Nevada	99
Newark	952		Rhode Island	91
Jersey City	462		Kansas	84
Washington, D.C. (Metro Area)	1184		Kentucky	84
Illinois		1103	Utah	70
Chicago	989		New Mexico	64
Pennsylvania		990	Arkansas	63
Philadelphia	792		Delaware	55
Massachusetts		865	Mississippi	55
Boston	637		Iowa	54
Georgia		841	Maine	48
Atlanta	654		Nebraska	35
District of Columbia		755	New Hampshire	35
Maryland		606	West Virginia	35
Washington		496	Alaska	34
Seattle	395		Vermont	13
Louisiana		481	Idaho	10
New Orleans	347		Montana	8
Virginia		464	Wyoming	8
Connecticut		461	Virgin Islands	7
Ohio		441	North Dakota	5
Colorado		424	South Dakota	5
Denver	353		Guam	1
Puerto Rico		394	Trust Territory	1
Michigan		379	Pediatric Cases (included in above)	583

Of these 23,559 (approximately 58 percent) are dead.

Source: New York Native August 24th 1987. (Compiled from Centers for Disease Control Statistics.)

Isolation and transmission

HIV has now been isolated from the amniotic fluid of one woman who had been an injecting drug user *but* most cases of HIV infection in the newborn are attributable to the transmission of the virus across the placenta during delivery. There have been reports that breast milk has been implicated in the post-natal transmission in two cases in Rwanda. In both instances, the mothers had received transfusions of HIV infected blood after the birth of their children.

Nevertheless, it is widely accepted now that the relative contribution of breast feeding to HIV transmission is probably small compared with that of inter-uterine transmission or transmission across the placenta at birth. The World Health Organisation recommended in July 1987 that breast feeding by the biological mother should continue to be the feeding method of choice irrespective of her HIV infection status. This conclusion is reached because of the benefits to be derived from breast feeding in both developed and developing countries and because of the low reported incidence of transmission via this route.

The Human Immunodeficiency Viruses

It has now been discovered that there is at least one other retrovirus that cause AIDS and similar illnesses. This virus which has been called HIV–II is found in certain well-defined population groups in West Africa and also in Portugal and Brazil. HIV–II produces different antibody responses from HIV–I, and this has implications for the further development of antibody tests to detect infection as well as for vaccine development. Double infection with both viruses has also been shown to occur.

The Consequences of HIV infection

A recent study has confirmed previous findings relating to the average length of time between HIV infection and the diagnosis of AIDS. According to an article by Anderson & Billard (in Nature 328, 719-712), the average period was found to be 1.97 years for children aged 0-4 at the time of transfusion, 5.5 years for men and 8.23 years for women. Care needs to be taken in extrapolating from these statistics to cases in which HIV is transmitted in other ways. Additionally, this data relates only to those people who subsequently developed AIDS after receiving a transfusion of infected blood.

The natural history of progression to AIDS from another symptomatic state is also becoming better understood. At the Third International Conference on AIDS in Washington, DC, statistics were presented detailing the medium to long-term consequences of Persistent Generalized Lymphadenopathy. Of a group of 200 gay men with PGL studied at the University of California, San Francisco, 3.5% had developed AIDS after two years, 13% after three years, 32% after four years and 45% after five years.

Pregnancy and HIV infection

Studies in progress are tending to question the view earlier expressed that pregnacy in a woman with HIV infection will increase the likelihood of her further developing AIDS. Currently, there is no evidence to suggest that abortion will affect the outcome of pregnancy in a woman with HIV infection for the better.

Injecting drug use and HIV infection

Concern has recently been expressed about the effectiveness of bleach as a means of cleaning syringes and needles between use. Typically, bleach loses its strength over time and unless fresh supplies are used there is the possibility that disinfection may be less efficient than it should be. The AIDS information officer at SCODA can provide up to date information on the most appropriate methods of disinfection (1/4 Hatton Gardens London EC1N 8ND).

Therapy

Studies of the effectiveness of AZT (now known widely under its trade name of Retrovir) continue to suggest that it is effective in relieving symptoms and prolonging life after the diagnosis of AIDS. A number of other drugs are currently undergoing clinical trials in the United States including DDC (Dideoxycytidine) – a substance very simular to AZT, DTC (Immuthiol), CS-85 and Ribavirin. Additionally, trials of the double stranded RNA compound Ampligen have resulted in clinical, virological and immunological treatment without significant side effects. There has been considerable discussion recently about effectiveness of the substance AL 721 as a therapy for AIDS. AL 721 is a food substance made from enriched lecithin, butter and water. Medical opinion in Britain is currently sceptical about the claims that have been made for this substance.

Vaccines

About twenty prototype vaccines are currently under study. A number of these have been shown to stimulate the production of antibodies in laboratory animals but these antibodies seem so far to offer little protection against subsequent HIV infection. Vaccine trials involving humans are about to commence in the United States but little is yet known about the likely effectiveness of the vaccines which these will involve.

Condoms

The consumer magazine WHICH published a buying guide to condoms in its September, 1987 edition. This identifies the strongest condoms currently available as well as those which are coated with the spermicide Nonoxynol – 9 which has been shown to inactivate HIV under laboratory conditions. Not reported in the WHICH survey is a new condom produced by Warner Lambert called Lifestyles Extra Strength which its manufacturers claim is 20 – 25% stronger than other condoms.

Insurance

The association of British Insurers recommended in May that its 425 member companies should question applicants for life insurance abour AIDS and all insurance companies have agreed that applicants with HIV infection will be denied cover. As yet there is some variation in the way in which insurance companies ask applicants whether or not they have had a blood test in relation to AIDS and some companies have begun to ask supplementry questions about sexual lifestyles.

Testing for HIV.

At the British Medical Association's annual conference in July it was resolved that testing for HIV should take place at the discretion of the patient's doctor and should not necessarily require the consent of the patient – a resolution which has since generated considerable debate both within the BMA and elsewhere. The Medical Defence Union has subsequently criticised this decision on the grounds that doctors pursuing this course of action may be subject to legal action on the grounds of charges of abuse to the person. The BMA AIDS Working Party is currently considering the implications of this decision for future professional practice. The UKCC has made it clear to nurses who 'knowingly collude' with a doctor in obtaining blood specimens for HIV testing without consent that they could be charged with aiding and abetting assault.